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ABSTRACT

Presented are seven papers given at a conference on deinstitutionalization of the mentally handicapped which focus on protective services and citizen advocacy. Carol Sigelman stresses the following four concepts: follow-along (the monitoring of the developmentally disabled person in the community), advocacy, protection, and shelter. Alternatives for the provision of protective legal services for the developmentally disabled are considered by Gerald Bensberg. The present status and implementation of concepts of citizen advocacy in Nebraska are reviewed by Helen Zauha. Marie Moore describes a United Cerebral Palsy Association demonstration project of three models of advocacy programs which take into account demographic variables, differences in service availability and delivery, and differences in organization patterns. Parameters, definitions, and alternatives for protective services in Ohio are examined by Elsie Helsel. Phyllis Emory and William Parks also review aspects of protective service and public guardianship in Ohio. A critique of protective services in general and the Ohio protective services system in particular which centers on the need to protect the civil and human rights of the developmentally disabled is offered by Michael Kindred. Appended is the text of the Ohio Protective Service Law. (DB)

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PROTECTIVE SERVICES AND CITIZEN ADVOCACY

Edited by

Carol K. Sigelman

Research and Training Center in Mental Retardation

Monograph No. 3

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FOREWORD

The Research and Training Center in Mental Retardation at Texas Tech University is one of several facilities supported in part by grants from the Research and Training Centers Division of the Social and Rehabilitation Service in HEW. The Center's major purpose is to initiate applied research which is aimed toward alleviating disability, reducing dependency, and formulating more effective rehabilitation service delivery systems. The Center also seeks ways to share its research findings with and participate in the training of mental retardation and vocational rehabilitation personnel in the states of Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

During the 1972-1973 grant year, the Texas Tech Research and Training Center, under the direction of Dr. Gerard J. Bensberg, planned and conducted several conferences for representatives from the five states. Five of these conferences, made possible by an SRS project grant, centered on the theme of deinstitutionalization and the development of community services. Monograph No. 1, *Group Homes for the Mentally Retarded*, described community residential programs as alternatives to institutionalization. Monograph No. 2, *Behavior Modification in Three Settings*, presented innovative applications of behavior modification in teaching social and vocational skills to the developmentally disabled. The present publication, *Protective Services and Citizen Advocacy*, is the third and final report on the deinstitutionalization conferences. The papers included in the monograph were presented at a conference held February 19-21, 1973, at Texas Tech University.

Thanks go to the presenters and to the participants for making it a fruitful conference. Special thanks go to Katherine Adams for her careful preparation of the manuscript for print.

PROTECTIVE SERVICES AND CITIZEN ADVOCACY: AN INTRODUCTION

Carol K. Sigelman

It is fitting that one of the topics in a series of conferences about deinstitutionalization be protective services and citizen advocacy. In an institution, the individual is supplied with basic needs and protected from adversity; once moved to the community, he or she is faced with greater responsibility and greater risk. Deinstitutionalization, though a popular catchword, is hardly an end in itself. The ultimate goal is not simply to swing open the gates, but to offer the developmentally disabled a better quality of life and more appropriate rehabilitative services outside the institution than they had enjoyed within the institution. The development of a network of community services will not only benefit those leaving institutions but also reduce the number entering institutions.

What are the needs of the developmentally disabled in the community? Wolf Wolfensberger (1972), in developing the Nebraska model of citizen advocacy, emphasized the distinction between *instrumental functions*—those which have to do with managing one's life and meeting one's daily needs—and *expressive functions*—those which concern affection, companionship, and a feeling of self-worth. The developmentally disabled person in the community may require help in meeting both his instrumental and expressive needs. On the one hand, he may need help in applying for Supplemental Security Income benefits; on the other, he may need a good listener after a hard day at work. Some individuals may require aid in one area but not in the other.

According to Wolfensberger, most social service agencies are better equipped to meet instrumental than expressive needs, but even their ability to respond to instrumental needs is limited. For example, a community agency may be able to place an adult in a new vocational training program or locate a suitable residence, but may be unable to respond to daily requests for help in replacing lightbulbs, shopping for food, or transferring from one bus to another. Along with deinstitutionalization must come an expansion of existing community services and the development of new types of service programs. However, Wolfensberger and others who propose either citizen advocacy or protective services seem to be saying that the existence of community services is not enough. Someone must help the developmentally disabled locate appropriate services and insure that those services benefit the individual. Furthermore, someone must help the developmentally disabled solve daily problems in community living and find fulfillment in interpersonal relationships.

THE RESPONSE: FOUR CONCEPTS

Although no solid evidence is available to suggest which needs of the developmentally disabled are most pressing, four closely related concepts have evolved in response to presumed needs.

The Concept of Follow-Along

While the resident of an institution is watched and evaluated as he progresses through programs, the developmentally disabled person in the community often disappears from sight, partly because of a desire to break ties with the institution,

partly because of a lack of long-range and consistent follow-along services. The concept of follow-along means not cloak-and-dagger surveillance but a monitoring of progress, with the objective of achieving better matches between needs and services. Follow-along seems to be an essential element of advocacy and protective service models, for only by tracking the individual and serving as "watchdog" can the helper determine when needs are unmet. The establishment of full-fledged aftercare units in many institutions suggests that institutions are beginning to take on the responsibility of watching what happens when someone leaves their direct supervision.

The Concept of Advocacy

Advocacy means actively promoting and helping to achieve the goals of another person. Wolfensberger (1972) defined a citizen advocate as "a mature competent citizen representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention." Wolfensberger conceptualized a number of advocate roles, ranging from those which resemble natural friendship relationships to those which are legally sanctioned. Although this implies a rather broad definition of advocacy, the essential element is providing help and affection where it is needed *and* wanted. The one-to-one relationship provided by an advocate has unique potential for meeting needs which large service agencies cannot meet.

The Concept of Protection

Protection, although it is at times difficult to distinguish from advocacy, concerns safeguarding the rights of the developmentally disabled—by insuring that they receive appropriate services and by preventing their abuse—through either an informal relationship or a legal arrangement such as guardianship. In the past, the concept of protection has taken the form of guardianships, conservatorships, trusteeships, and so forth—all centered largely on the protection of property and person. Those who argue for protective services emphasize the need for relationships which protect the person's rights to citizenship, meaningful rehabilitation, and a decent standard of living. The protector, in contrast to the advocate, has more leeway as a substitute decision-maker and more clients with whom to work. In practice, advocates and protective service workers may perform many of the same functions, but typically the advocate is a citizen rather than a paid professional, and the protective service worker, while he is to operate without interference from an agency, is an employee subject to certain constraints.

The Concept of Shelter

The concept of shelter, more than the first three concepts, entails actively changing the environment of the developmentally disabled person. Instead of protecting rights or helping with daily problems as they arise, we may establish a less-than-independent environment which reduces the probability of certain problems arising in the first place. Through sheltering, the demands placed on the developmentally disabled become more congruent with their competencies. Sheltered workshops, as well as halfway houses, group homes, and crisis

intervention centers, help, in part, by reducing demands and preventing risk.

Sometimes the developmentally disabled are fortunate enough to have all four concepts working for them naturally. For example, Edgerton (1967), in his intensive study of mildly retarded adults released from Pacific State Hospital, found that many of his subjects were helped through life by "benefactors," often landladies, relatives, employers, or neighbors who took it upon themselves to observe how the individual was getting along, serve as a friend to him, help him cope with crises, and shelter him by handling many responsibilities for him. Drawing from the same four concepts is the much more formalized system represented by Ohio's Protective Service and Public Guardianship system, which leaves very little to chance. The protective service worker's first function is to monitor and evaluate, but he or she may act as a client's advocate if the client has grievances, establish a formal guardianship if the client requires legal protection, or even act to lessen the demands placed on the client by helping to place him in a more sheltered environment.

Although more questions may be raised about a formal system than about an informal system, legal and ethical problems arise any time one person attempts to "help" another. The key question is this: To what extent does the help infringe on the developmentally disabled person's rights or subvert his goals? The helper must continually decide when to help and how to help. The new concepts of advocacy and protective services, unlike older forms of guardianship, suggest limited power but do not specify boundaries of power. If, for example, a person wishes to consume nothing but martinis, drawing sustenance from the olives, is it his or her choice, or is it a choice subject to influence by the helper? If we take the word "advocate" literally, should the advocate intervene and work against his protégé's interest in drinking martinis? As a helper, the advocate is tempted to say, "Protégé, you really don't know your own interests as well as I do." If he decides to intervene, should he stop with a "friend-to-friend" chat, should he withhold his positive concern until the client reforms, or should he call Alcoholics Anonymous? If he intervenes forcefully, by confiscating the liquor supply, is he in any way liable if the protégé breaks into a liquor store or slashes his wrists? The example may stretch the imagination, but any helper faces real difficulties when his values conflict with those of his client, particularly in such personal areas as sex and life style. Although citizen advocacy has a strong voluntary thrust, it, like protection and shelter, can be seen as arising out of a control orientation, as Michael Kindred suggests later in this collection. Even the concept of follow-along raises eyebrows, particularly when it comes to how information is used and to whom it is revealed. Consumer groups fighting to limit the collection of information about private citizens by governmental agencies and credit bureaus can use the same arguments in criticizing follow-along services for the developmentally disabled citizen.

In a nation which tends to believe that "bigger is better," it will be difficult to avoid overprotection. Yet, those who argue for citizen advocacy and protective services appear to recognize that least may be best. One of the major limitations of earlier protective service plans, for example Minnesota's public guardianship system, was that they tended to operate in an "all-or-nothing" fashion (Wolfensberger, 1972). The strength of new plans is that they attempt to provide a continuum of helping relationships so that the mildly retarded adult who can meet his basic needs does not become locked in a full-scale guardianship. Helpers must continually reexamine their roles and provide the minimal amount of follow-along, advocacy,

protection, and shelter needed by each individual. This rule of thumb does not solve the legal issues of control, but it suggests that the programs to be described in this monograph differ in many ways from direct service programs which seek to provide more service to greater numbers of people.

It also suggests that we may need to be creative in developing evaluative measures of advocacy and protection programs. Counting the number of contacts or interventions per client is clearly an inadequate index of effectiveness if we take seriously the dangers of overprotection. We would want to correct somehow for the number of instances of "overkill" or infringement of rights by helpers. Although it is difficult to design such research, researchers might take on the task of comparing different models for helping the developmentally disabled adjust in the community. If such a research study took the form of a follow-up study of people released from institutions, the most important yardsticks of a program's success would be those pertaining to the individual's quality of life—extent of self-support, employment status, reduced need for direct services, standard of living, satisfaction, and integration into the life of the community. Client outcomes could be correlated with program characteristics such as size of staff, per client expenditure, number and type of intervention, and so forth. It is only through such research that we will determine whether a group of unpaid volunteers given minimal administrative assistance is more or less successful than a cadre of professionalized protective service workers, and whether either citizen advocacy or protective services is better than nothing. It may be that citizen advocacy and protective services are not alternatives, but complementary models which meet different needs and work best in tandem, as is assumed in Ohio's overall service plan.

CONTENTS

The programs described in this monograph are important in that they are likely to serve—and indeed, have already served—as models for other programs. The authors readily admit that their models are not final solutions, but the papers suggest several directions in which to proceed.

The first paper, written by Dr. Gerard J. Bensberg, Director of the Texas Tech Research and Training Center in Mental Retardation, is a brief introduction to the potentials and pitfalls of citizen advocacy and protective services. Next, in "Citizen Advocacy—Present Status and Implementation in Nebraska," Helen Zauha, Coordinator of the Citizen Advocate Program of the Greater Omaha Association for Retarded Children, lays out the Nebraska model of volunteer advocacy. Marie L. Moore, National Advocacy Coordinator for a special research project being conducted by United Cerebral Palsy Associations, Inc., describes a variety of advocacy tactics which are being tested across the country. Her paper, "A Demonstration of Three Models of Advocacy Programs for Developmentally Disabled Children," focuses on organizing community-wide efforts, starting with a determination of needs in different regions.

Three papers on protective services provide a balanced view of the model developed in Ohio. Dr. Elsie D. Helsel, Washington representative for United Cerebral Palsy, lays the groundwork by telling how and why the protective services plan was developed. Phyllis Emory and William Parks, who adminster the Ohio Office of Protective Service and Public Guardianship, describe in some detail how the program is structured and how it is progressing. Finally, in the role of critic,

comes Professor Michael Kindred of the Ohio State University College of Law. In "Protecting the Civil and Human Rights of the Developmentally Disabled," he not only raises general questions about control and protection of rights which apply to protective services and citizen advocacy, but he points out specific weaknesses in the Ohio protective service law, which is presented in Appendix A of this monograph.

The present volume is not a manual for establishing a program, but it is hoped that it will aid in making choices as to what type of advocacy or protection service is needed.

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PROTECTIVE SERVICES FOR THE DEVELOPMENTALLY DISABLED

Gerard J. Bensberg

Most of us follow a natural path as we grow to maturity. Also, for most of us, our parents are our legal guardians until we reach maturity. Although it is sometimes with reluctance, our parents give us increasing freedom as we move from infancy to childhood and through the teen years, as well as guard our rights. As a result, we are prepared to make wise decisions about the course of our own lives. This is clearly not the case with many developmentally disabled, particularly those with mental retardation. Many agencies and citizens, as well as parents, acting with the best of intentions, infringe upon the human and civil rights of the developmentally disabled. Recent pressure by parent groups and resultant court suits have made us acutely aware of instances of infringement on the rights to treatment: being forced into involuntary servitude, lacking protection from abuse, and failing to receive due process and equal protection under the law in such matters as commitment to an institution, voting, and making contracts.

In some court hearings we have been made aware of instances of abuse and mistreatment which were obviously just cause for bringing libel suits against the individuals who were guilty of such actions. However, in the majority of situations, the injustices exposed seemed to be more related to historical traditions and the lack of adequate staff and financial support to provide such rights as comprehensive education and payment for work performed. In many cases brought to light, the administrators had repeatedly asked for more funds to improve difficult situations but were refused.

Public agencies providing services to the developmentally disabled have been accused of being too rigid and impersonal. Because of large case loads and high staff turnover, many individuals are "lost in the shuffle" or their individual rights are subsumed under the rights of the group for ease of program administration. As a result of litigation and pressure from various citizen groups, attention is now being given to the rights of the handicapped and ways in which these rights can be assured.

One approach has been to create a separate division or agency which is specifically concerned with the provision of protective and related services. These functions usually include outreach and prevention, counseling, coordination of services, tracking and following along, case auditing and case management, as well as the more traditional guardianship services. There are, of course, problems associated with one group of employees making sure that another group of employees do their job well. Job tenure and promotion may relate more to helping the agency reach its goals than to helping handicapped individuals achieve their goals. Some states have attempted to give the protective service agency more power and independence by appointing a citizen committee which would oversee its work and report any inadequacies noted to the administration or to the public.

An alternative to the creation of a public agency which has been explored by some states is the creation of a citizen advocacy program. In most cases, these programs have been sponsored by a citizen group such as an affiliate of the United Cerebral Palsy Association or the National Association for Retarded Citizens. Citizen advocacy refers to the response of private citizens to the needs of others

. . . as a friend . . . a protector . . . an advisor . . . and guide. Obviously, this approach also has its limitations. An individual might volunteer to serve as someone's protector, more to meet his own personal needs than to meet the needs of his protégé. He would also need to be somewhat aware of strengths and weaknesses in programs in order to be constructive in his criticism of state and local agencies.

A basic problem, still unresolved, is that of deciding who should have protective services and how broad these services should be. How do we make a system flexible enough to respond to the varied needs of the developmentally disabled which still does not overprotect? What system can monitor the progress and problems of individuals but not invade the privacy of the individual? How can the system be organized on a systematic basis to be accessible to all and yet personal enough to respond to the needs of an individual?

Perhaps as we study the various models now being employed, we will find a way of resolving the problems inherent in each. The best solution at the moment seems to be some type of balance between a professional protective agency and citizen advocacy input. In our zeal to improve services to the developmentally disabled, we must be careful not to "overprotect" or destroy the agencies struggling to meet their needs. The papers in this collection will help to provide insight into these problems.

CITIZEN ADVOCACY—PRESENT STATUS AND IMPLEMENTATION IN NEBRASKA

Helen Zauha

Dr. Wolf Wolfensberger first organized the citizen advocacy concept and schema in 1966, designing it to complement or supplant traditional protective services for handicapped persons. Since that time, nearly 40 local efforts have begun across the North American continent. In this paper notable features of citizen advocacy will be discussed based on Wolfensberger's ideas and experiences to date in the pilot state—Nebraska.

CITIZEN ADVOCACY FEATURES

Varieties

Citizen advocacy refers to the response of private persons to the needs of other people. This response is specifically encouraged on an individualized basis by Citizen Advocate Programs, though a variety of supportive and complementary functions can be performed by private citizens in groups or as individuals, as, for example, pressure groups or sympathetic contact persons.

Citizen advocacy affords great variety in the type of role or supportive relationship that can be formed between a citizen and handicapped person. Roles range from short-term to long-term, informal to formal. Ages and functions of advocates are as limitless as the number of age combinations and types of helpful relationships that are already existing in some natural form in our society.

Special Contribution

Stress is placed on citizen competency. For persons seeking adjustment in the community, no one could be a better ally than a member of the community. The private citizen can provide a service to another in a way which a professional or family member cannot. The citizen advocate usually will not duplicate parental and professional functions, though he may undertake such functions if they are not otherwise performed. He will be adding a vital new component to his protégé's (person with an advocate) world—someone who is involved only because of the inherent value of his protégé. He receives no pay, has no blood-tie responsibility. His caring proves a great inspiration and impetus to both parent and professional as they determine the directions of their own relationships and programs. Their child or client is and can be accepted in the community. The citizen advocate demonstrates this and will work to insure future acceptance.

In addition to his influence on parents and professionals, the citizen advocate has a unique influence on the rest of the community. He is in a position to involve previously negative or neutral friends, family members, and others in an active acceptance of and participation with handicapped persons. He does this by encouragement, example, and active persuasion.

Purposes of the Advocate

Advocacy means to be in favor or support of something. A citizen advocate to an impaired, handicapped, or disadvantaged person is *for* whatever is in the best

interest of his protégé. The best interest of a handicapped person is seen to be similar to what is seen as best for all other persons in a society. Like all of us, the impaired, handicapped, and disadvantaged should be given a chance to grow, learn, and develop capabilities and potentials. Like all of us, the handicapped person needs to be treated as a human being with feelings and desires, to be special, to receive respect, and to know that he is liked. Like all of us the handicapped person has the rights of citizenship and participation in the community. An advocate is for the removal of unnecessary, discriminatory distinctions which are or would be harmful to his protégé. Advocates are selected, in part, on the basis of their agreement with these beliefs.

Primacy of the Advocate

In line with the concept of citizen competency, it is the advocate who does the advocating. He is not to be upstaged by the Citizen Advocate Program staff or office. The staff and office and various back-up mechanisms, such as professional or experienced consultants and special interest committees, are available to support an advocate on request. The advocate may be given suggestions and guidance, but it is he who makes decisions as to his best action on behalf of his protégé. This is essential to the success and effectiveness of citizen advocates. The office could never serve handicapped individuals as effectively as strong, self-initiating, responsive citizen advocates.

The office which coordinates the Citizen Advocacy Program only facilitates citizen efforts. The professional staff publicizes the program and screens, orients, and matches participants. After matching, the staff may mediate meetings between advocates and other consultants. It generally works to steer advocates toward strong, healthy, reliable relationships. The staff continues to discuss progress and possibilities with advocates because all relationships are continually changing and evolving. Mediation of formal roles such as adoptions or guardianships should also be a capability of a Citizen Advocate Program office.

Longevity of Relationships

The office primarily seeks to foster relationships which will last over time on the basis of need, but when relationships fail to last, the office helps to keep the program running smoothly. Some advocates terminate or discontinue for a variety of reasons. In such cases, the office assesses the need for replacement relationships. In addition, some advocates need reassignment because of a protégé's leaving, death, or lack of ongoing need for an advocate. The advocacy office can do much to pick up the threads by reassignment or additional assignment.

Advocacy relationships may be terminated by the protégé -when, for example, he discourages the advocate with nonreceptivity or direct refusal–by the advocate himself, or by the courts. The Citizen Advocacy Program may counsel an advocate and/or make additional assignments of advocates to a particular protégé, but it cannot remove an advocate by whim or because of a difference of opinion, nor can other agencies or persons if the advocate is acting within the law. Parents, of course, would probably have more to say with respect to their minor child.

Quite simply, the advocate functions in roles which are natural and acceptable in society–as friend, guardian, adoptive parent, or guide-counselor. His range of

activity is that which would normally be lawful in each role. He has a right to a difference of opinion and should be free to influence or be modified by others accordingly.

Avoiding Conflict of Interest

The Citizen Advocacy Program office should be as independent as possible of the service deliverers. An essential of citizen advocacy—the identity of the citizen advocate—may be fragile in the initial stages and is greatly influenced by the extent to which the advocate feels that he is an independent (though supported) agent. If his relationship takes life through the coordination of the service agency, his decisions in behalf of his protégé will tend to take that agency into account. He will be more their advocate than his protégé's. Beyond the level of perceptions, the advocate so spawned would probably be subject to real limits on his behavior as a sponsor. The agency would be sorely put to tolerate much rankling and could easily disregard even very diplomatic suggestions.

The more the private sector can be drawn upon to buttress the program, the more strongly instituted the program will be. The professionals have their jobs to do; the families have their responsibilities to handicapped members. What is needed along with their efforts is a strong, independent, additional line of force to accept and integrate the handicapped in the community.

Parents and professionals must not use the advocate for their own designs, but rather must realize that his first loyalty is to their child or client. Parents and professionals must be encouraged to loosen their exclusive hold on the handicapped person and to respect, welcome, and foster the development of the citizen advocate and of the community response and support system which he represents. They should continue their own development while appreciating the new point of view and the objectivity which an advocate can provide. They should not weaken him by diverting his energies to their own designs (i.e., by giving him babysitting chores or handing him staff functions).

Because of the newness of the emphasis on citizen contribution and representation, the independence of the advocate from the office and from office funding demands particular concern. Some compromises may be necessary, particularly in the area of funding, but independence should be stressed in order to foster support and successful representation of the handicapped by the private sector.

Recourses and Resources

Citizen advocates have a number of recourses and resources which can help them in their efforts on behalf of another person. As has been said before, they operate in naturally existing roles. As citizens, they work in ways in which private persons naturally work. For instance, unlike the professional or even the office staff, a citizen advocate can contact persons up and down the line in a service delivery system—the counselor, the counselor's boss, or the counselor's boss's boss—or even shift out of the system to contact parents or professionals in another agency. A staff or professional person's doing this might be taken as breaking faith and cause a coolness and lack of cooperation between professionals. The citizen cannot be retaliated against in this way.

The advocate's ability to sway others or change a course of action is limited only to the degree that his daring and staying power are limited. He can use direct example and persuasion on his protégé, parents, or professionals; he can influence others—for instance, a committee, a rival professional, a parent, an association, friends or neighbors, or even news media or courts—to apply pressure. All of the ways in which people persuade or influence each other are open to him. He cannot be fired; he cannot be kept from his relationship. He can choose to reinforce or cooperate with a plan or program developed by parents or professionals for his handicapped friend if he thinks it is best. Or he can do all within his power to prevent a course of action by parents or professionals which he sees as detrimental to his protégé. His first interest is his protégé's welfare.

THE NEBRASKA EXPERIENCE

Having laid out the general concept of the citizen advocate, we can now describe the evolution of citizen advocacy in Nebraska. Two models of citizen advocacy in the state will be described. Existing "protective services" will be examined briefly to suggest functions which complement citizen advocacy services for the retarded.

Community Services

Due to the influence of a Governor's Citizens' Committee and legislative action in 1968, a new Nebraska State Plan for Services to the Mentally Retarded was issued. It allowed for a gradual reduction in the population of the major state institution for the retarded and for the development of community service programs in six regions across the state to serve these people and other retarded persons in their home communities. Each region was to have services available for every age group and degree of disability. These local service operations were not to duplicate existing services and, in fact, were to actively foster service integration of retarded persons in existing schools and agencies. The goal for regional offices was to eventually coordinate services and to actually stay out of operations once full integration of the retarded was accomplished.

The service delivery region in eastern Nebraska is administered by ENCOR (Eastern Nebraska Community Office of Retardation). There are four major divisions of professional services: (1) Developmental Services for children to age 16; (2) Vocational Services for persons over age 16; (3) Residential Services for persons of all ages in a variety of types of residences (homes, group homes, apartments, etc.) and (4) Supportive Services, including transportation, recreation, speech and physical therapy, testing, counseling, and so on.

Professional and Citizen Advocates

Counselors in Supportive Services take service referrals, work to develop and coordinate a service program for clients, follow clients along, and handle matters carrying over from one division to another. They also can provide a number of direct services such as finding jobs and lodging, obtaining services, getting funding for an individual, counseling individuals and families, and helping in the socialization of clients. The actual description of counselors' duties is not firm yet, and their relationship to other divisions is still evolving.

There are real similarities between their functions and those of protective service workers in Ohio. However, their case load is larger—around 50. Also, their relationships to clients are informal and their position as professional advocates within the service system is still not well delineated. At this time, their division is on, at most, an equal footing with the rest of the divisions, with no set channel of recourse to higher administrative persons or bodies (such as the executive director or advisory committee). If these channels evolve, the counselor may prove to be an increasingly effective professional sponsor of particular clients dealing with service agencies in the community.

A service system dedicated to full integration and participation of retarded or handicapped persons in the community must definitely be committed to changing itself and to increasing involvement in and by the surrounding community. This dedication implies a heavy degree of professional advocacy by those persons staffing the system. They must look to the time when they will go out of business; they must look to the time when the community will fully embrace the group for whom they offer special services.

A component for community support and monitoring of services was written into the 1968 Nebraska State Plan—the principle of citizen advocates for individual retarded persons. These citizen advocates would sponsor individual persons with an eye to the best possible service along the lines of normalization. Citizen advocates would help insure change within the system and integration of the retarded in the community. They would work to see professionals act effectively on behalf of their clients.

Implemented Programs

In 1970, the Capitol Association for Retarded Children in Lincoln, Nebraska, which had "spun-off" its direct services to the regional service agency, agreed to sponsor the pilot Citizen Advocate Program. An Advisory Committee was formed to consist of broad community representation. Members of this committee lent their expertise to both office staff and individual advocates. The Committee has been one of the best advocates of the Lincoln Citizen Advocate Program with the host ARC and in the surrounding community. Three years later, the pilot program has three full-time staff and 150 active advocates of a variety of ages performing a number of helpful roles. Funding for this program is through Title IVa and XVI Social Security Provisions. The local Community Chest provides the one-fourth local matching funds.

Late in 1971, the Greater Omaha Association for Retarded Children in Omaha, Nebraska, also began a Citizen Advocate Program. In fact, the whole ARC defines its role and function as a voluntary advocate for the rights and dignity of retarded persons and their families. The GOARC advocacy program would appear to be an integral part of the Association. The GOARC Executive Director and Board have been advisors to the program, though a separate committee will be formed in the near future similar to the one in Lincoln. Advocates are encouraged to take an active part in other GOARC thrusts in addition to their relationships with handicapped persons.

There are several complementary programs of GOARC which both involve and support advocates:

1. Pilot Parents is a type of citizen advocacy where veteran parents of retarded children offer support to newly identified parents of retarded children.
2. Human and Legal Rights Committees on Special Education, Vocational Services, Developmental Services, Residential Services and Public Attitudinal Change are committees made up of parents, advocates, youth, and other interested citizens which support and monitor special areas of concern.
3. Youth Volunteers (YARC) are individual advocates in Omaha and/or at the state institution. They plan and carry out group activities with retarded children and teens.
4. A Legislative Action Committee works to mobilize local GOARC members to support needed legislation.

GOARC citizen advocates who are in individualized relationships with retarded persons can use the above complementary programs. For instance, they can get Pilot Parents involved with the parents of a protégé; they can submit an unsatisfied grievance to an Action Committee or to a Human and Legal Rights Committee on behalf of their protégé and/or his family; and they can involve their protégé in youth group activities.

In the first year and a half of the program, nearly 80 citizen advocates participated in the GOARC Citizen Advocate Program. One-third were assigned to children, one-third to teenagers, and one-third to adults. The average age of advocates was in the mid-twenties. Nearly 150 potential protégés await assignment. At the time of this writing, an assistant coordinator has been obtained to assist with the program, bringing staffing up to two and a half persons. The program is funded temporarily with two loan positions and GOARC secretarial and administrative back-up.

The GOARC commitment appears to be a solid one despite the difficulties in obtaining funding. There is no question of the desirability of and demand for the Citizen Advocate Program in assimilating retarded persons in the community.

As of January, 1971, the Nebraska Association for Retarded Children was funded in a statewide project to encourage more local citizen advocacy programs through Developmental Disabilities funding. Through the efforts of a staff of two and a half persons, six local areas have set up study committees now committed to implement programs. They are seeking funding for program coordination with the assistance of the state project director. This project also lends coordination to a statewide youth advocacy program which fosters individual relationships between residents who now live at the state institution and people from their home areas.

Funding would appear to be one of the crucial future problems in organizing a coordinated community response to retarded or handicapped persons. As was stated earlier, however, funding from private sources is a very prime indicator of community response and/or citizen advocacy for the handicapped. We must look for support of citizen advocacy from the private sector to insure the survival of the program, the independence of the advocates, and the commitment of the community to inclusion of some of its previously excluded members.

OPERATING A CITIZEN ADVOCACY PROGRAM

By way of summary, I would like to present material from the proposal for the GOARC Citizen Advocacy Program, the parts which describe how services are provided. This material, by emphasizing the role of our office in coordinating the volunteer program, will suggest more specifically how a citizen advocacy program can be initiated and run.

The investment in staff to coordinate this program is minimal when one considers the number of volunteers that can be *enabled* to be good citizen advocates. Staff involvement is essential to this volunteer program in the following areas:

1. Public education to acquaint the community and citizens with a mentally retarded person's need for an advocate-volunteer.
2. Alerting and orienting parents and appropriate professionals to the need for cooperation with an anticipated advocacy relationship.
3. Active search for potential advocates and protégés—competent citizens of all ages and retarded persons of all ages and degrees of disability. Potential protégés are referred to the Citizen Advocate Program by parents, teachers, counselors, caseworkers, or other friends and interested persons in the community.
4. Screening and investigation of potential advocates and protégés. Potential advocates are interviewed as to past experiences, time available for a relationship, interest in various ages and degrees of disability, length of time in the community, transportation, and type of role qualified for and desired. The major qualification to become a citizen advocate is a desire for and ability to form a long-term, healthy relationship with a mentally retarded or multi-handicapped person. References are requested and are followed up if more information is needed. The receptivity of a potential protégé's family is checked if he is a minor, and the protégé's own feelings about the idea of a friend from the community are explored. Information is gathered on the person referred as needing an advocate in order to help match his needs with an advocate's capabilities. No service is extended to those persons who qualify as potential protégés, however, until an advocate is assigned.
5. Intense training of potential advocates. Before matching, volunteers are instructed as to their role as advocates. Experienced advocates relate their experiences. Particular emphasis is given to the rights and appropriate treatment of retarded and handicapped individuals. Suggestions are given for building a healthy relationship. This initial training is embodied in a series of three group meetings.
6. Matching of volunteers and protégés. After the advocate has attended three training sessions, possible protégés are suggested. An informal meeting is set up between the potential advocate, protégé and program coordinator. Only after meeting an acceptable protégé does the advocate commit himself to beginning to build a helpful relationship. After matching, the referring agency, the parent, or another involved person is notified and asked to direct any questions about the relationship to the program coordinator.
7. Continuing education and supervision of volunteers' relationships. Communication is maintained between the program coordinator and

advocates, particularly in the establishment phase of a relationship, through regular telephone contact at least once a month. After about two months, the advocate presents goals for the relationship to the program coordinator, who checks them over, initially for realism and periodically for progress. Because advocates serving in similar capacities can be helpful to each other, groups of no more than 8 advocates with similar assignments meet together monthly for six months with the program coordinator to discuss critical incidents. Resource persons can be called in on request to speak with individuals or groups of advocates. The coordinators stand by to assist in reassigning or terminating relationships if this becomes necessary, or in legalizing relationships into adoptions or guardianships if this becomes desirable. Many relationships which began informally become relatively stable or perhaps formalized, reducing the need for staff guidance and supervision.

The GOARC staff will usually have no formal contact with a protégé's family after an advocacy match. However, in critical situations, the program coordinator, after consulting with colleagues and reviewing the advocate's agreement, can directly intervene.

8. Evaluation of relationships and program. Annually, informal relationships are assessed. The protégé's situation at the beginning of the year, or at the time of advocate assignment, is compared with his year-end situation. Teachers, parents, counselors, advocates, and others report on observed changes. A retarded person's continuing or unmet needs for advocacy or relationships are assessed with an eye to reassignment or additional assignment of volunteer advocates. Observed increases in skill and self-reliance on the part of a protégé may be attributable to his advocate's involvement.

Some objective elements which can be measured to assess program success are:

a. Number and duration of relationships.
b. Number of services acquired for or with a protégé by his advocate.
c. Number of instances of representation of protégé interests by his advocate.
d. Frequency of contact with a protégé by his advocate.
e. Number of relationships with a legal basis.

A qualitative measure of individual advocate and program success is provided by an annual interview with each advocate for the purpose of evaluating the efficiency and depth of his relationship.

Progress in accomplishing the goals set by the advocate himself are weighed and reassessed. The advocate evaluates himself in writing, citing critical incidents and how they were solved, and honestly discussing what he likes and does not like about his experience as an advocate and about his particular protégé. This evaluation is constructively reviewed by the program coordinator.

Once again, it is important to say that the Citizen Advocacy Program staff need not be large, for its purpose is primarily to set relationships on their way and to support advocates as they provide service and assess their accomplishments. With very little expenditure, and with a few simple guidelines such as the ones listed above, a citizen advocacy program can add a new dimension to the lives of handicapped persons.

A DEMONSTRATION OF THREE MODELS OF ADVOCACY PROGRAMS FOR DEVELOPMENTALLY DISABLED CHILDREN

Marie L. Moore

Among the basic principles of services adopted by the United Cerebral Palsy Associations, Inc., is this imperative: "A lifetime partnership should be established from the time an affiliate and the family of a cerebral palsied individual come into contact. In effect, the affiliate would serve as a permanent resource for the cerebral palsied individual and his family." The partnership has been expanded to those individuals with developmental disabilities who have similar service needs.

Those individuals who have multiple problems associated with developmental disabilities often need the resources and partnership of a voluntary organization. The organization is able to work with a variety of community agencies, consumers, and concerned citizens in order to develop strategies that will result in meeting the needs of the individual and his family at the time they arise. These strategies include the facilitation of a variety of programs and services to meet the needs of the underserved and unserved disabled. The development of needed services may be through community organization methods, development of services by the affiliate, or legislative action.

ANALYSIS OF THE PROBLEM

The problems of the multi-handicapped with developmental disabilities are related to many dilemmas. Among the chief problems are the following:

1. The dilemma of the *primary diagnosis* where individuals are excluded from services due to several handicapping conditions; i.e., children who are blind, deaf, *and* cerebral palsied do not qualify for programs that are exclusively for blind, deaf, *or* cerebral palsied.
2. The dilemma of the *isolated special placement* in an educational program versus the opportunity for integration coupled with special resources.
3. The dilemma of *limited alternatives for housing.*
4. The dilemma of *social isolation* and quasi-segregation.
5. The dilemma of *limited vocational opportunities or alternatives* (along with the lack of developmental experiences for vocational preparation).
6. The dilemma of *limited financial assistance* for costs associated with the disability.
7. The dilemma of *limited mobility* in a mobile society.

These problems, which suggest the need for advocacy programs to solve them, may be examined in light of the following questions about the relationships between an individual and a service delivery system:

1. How does the individual enter the service delivery system and what are the barriers to his entry?
2. How are the services paid for?

3. How does the consumer get involved in the decision-making process relative to policies and practices of the service delivery system?
4. How does the consumer monitor the quality of service and become knowledgeable about his right of appeal?

Solutions to these questions are being sought through the development of three models of advocacy to be described later. In addition, we have identified three types of barriers which must be removed if effective solutions are to be found and implemented:

1. Physical barriers which require structural changes or the design of new devices to make buildings, transportation systems, and daily living necessities accessible to the handicapped so that they may function as independently as possible.
2. Attitudinal barriers which require public education for changing the attitudes of decision makers, planners, and providers of service.
3. Priority barriers which often determine who will be among the privileged receiving service—cost analysis and ranking by potential for the development of competency are two factors which deny services to severely handicapped people.

THE THREE DEMONSTRATION PROJECTS

In the context of this analysis of the problems and needs, three models of advocacy have been developed by UCP in one of its eleven projects of national significance. The overall advocacy project revolves around three major concepts: (1) a lifetime partnership involving UCP and the individual and his family; (2) information, referral, and follow-along services; and (3) the development of legislation. The project is designed to develop and demonstrate three models of advocacy programs which can take into account variations across the country. First, advocacy models must be able to serve different segments of the population—specifically, rural, suburban, and urban areas of differing socio-economic makeups in distinct geographical regions. Secondly, the project must take into account varying patterns of service availability and delivery. And finally, the models must be applicable in UCP affiliates with differing organizational patterns and programs.

The project sites were selected on the basis of this concern for developing models which can be applied in a variety of settings. The first site, in New York State, is an Eastern affiliate with family and community oriented programs for total management and advocacy. The geographic region includes urban, suburban, and rural areas with a range of socio-economic levels. The second site, Milwaukee, is a newly organized affiliate in a highly industrialized Midwestern city with a diverse population, including a large black minority. Milwaukee has many highly professionalized agencies providing services to developmentally disabled children. The third site, San Mateo/Santa Clara Counties, represents still another constellation of circumstances. Two West Coast affiliates sharing the same professional and administrative staff serve sprawling suburban areas with a large Spanish-speaking segment. Although there are several official and voluntary agencies in the area, there is no private agency with responsibility for providing advocacy services to handicapped children and their families.

The UCP project is staffed with a National Project Director, a National Advocacy Coordinator (myself), a coordinator in each of the three project areas, and a total of four secretaries. In addition, the project has built-in means for hearing from the consumer. Project Advocacy Advisory Councils composed of consumers (parents and handicapped adults) and providers of services from a variety of professions and service delivery systems guide the project. There is a National Advocacy Advisory Council consisting of nine consumers and eight professionals. In addition, there is a local council in each of the three areas, each with representation on the national council.

The three models of child advocacy being developed have as a focus steering children with developmental disabilities into appropriate services to meet their needs when these services are needed. The emphasis is squarely on the underserved and unserved who are in those categories for the following reasons:

1. Lack of services in the geographic area (often rural and inner city areas).
2. Restricting criteria for admission to programs, as when the consumer does not meet physical, intellectual, sensory, or financial requirements.
3. The restriction of available services by caseload sizes and the existence of long waiting lists.
4. The lack of referral services, even when comprehensive diagnostic services are available, to get individuals into appropriate programs at the appropriate times.
5. The lack of casefinding and follow-along services for minority groups.
6. The lack of consumer participation in community organization and planning, especially among those consumers who are not affluent or influential enough and among those who have substantial handicaps.
7. The lack of coordinated planning and services to permit placement and retention in the community as an alternative to institutionalization.

The long range goals and objectives of the program are ambitious. They have been set forth as follows:

1. To assist children with developmental disabilities and their families in obtaining needed services and making the best use of available resources.
2. To collect and collate data of various kinds in regard to service needs of children with developmental disabilities to be used by local, state, and national organizations for developing necessary legislation at all levels of government.
3. To work with legislative bodies and governmental agencies in the utilization of project findings and implications.
4. To work with consumers and consumer groups to urge their participation in community organization, planning, and legislative processes.
5. To work toward implementing the greater use of existing official programs.
6. To assist those from among 300 UCPA affiliates requesting consultation for replication of the Advocacy Models.
7. To evaluate the effectiveness of the Project's three developing models of advocacy and the coordinating activities of the National Staff as it affects meeting the needs and insuring the rights of developmentally disabled children.

8. To cooperate with other organizations and projects, both public and private, in their advocacy activities for meeting the needs and insuring the rights of children with developmental disabilities.

FIRST ACCOMPLISHMENTS

The following examples of program activities represent only the first period of operation from the fall of 1972 to December 31, 1972. They suggest, however, the directions that the program has started to take.

In the New York State site, an education program for severely handicapped children has been established in Malone, New York, for children who had been excluded from the public school system programs. In addition, a clinical and treatment facility was established in Essex County. The New York State Coordinator and the local Home Service Director combined efforts to establish this facility for formerly unserved children. In another effort, a commitment was made by UCP affiliates in Buffalo, Rockland County, Nassau County, and Westchester to establish and operate community residences or hostels. With one hostel developed in each of the four areas, there will be an improved capacity to serve young adults who are candidates to be discharged from state institutions. Finally, as a result of inservice training, several Home Service Directors are now engaging in advocacy activities on behalf of the clients on their caseloads.

In just a month of employment in 1972, the Milwaukee Advocacy Coordinator was able to establish several contacts and spur action. Contacts and relationships were established with approximately twenty service organizations and one parent organization in order to get their support for the UCP Advocacy Project. As a result, the local organization has become increasingly visible as a common resource through which to concentrate attention on unmet needs and problems in service delivery. The Advocacy Coordinator was also appointed to some key task forces and committees devoted to child advocacy on a statewide and local basis. One outcome of contacts with agencies was the stimulation of service agencies in the inner city to consider the needs of the developmentally disabled in their areas, along with the needs of other inner city residents. Finally, by the first of 1973, the Milwaukee project was in the initial planning stage of a community-wide, inter-agency-supported information, referral, and follow-along program, with specific emphasis on "high risk" infants and inner city children. Along with this a casefinding program in the inner city was planned.

The San Mateo/Santa Clara Advocacy Coordinator, like the Milwaukee Coordinator, spent the first months in laying the groundwork by: (1) establishing a local Advocacy Advisory Council; (2) establishing priorities as to which children, by age groups, ethnic groups, and geographic location, had the greatest need for services; (3) developing cooperative relationships with forty individuals representing many professions and service agencies to support the UCP project; and (4) establishing relationships with three consumer groups to explore their needs and levels of involvement in service planning.

CURRENT ACTIVITIES

Based upon the groundwork laid in 1972, 1973, and 1974, we project increased effort in several areas. Of first priority are objectives which result in children and their families getting better service to meet their needs. We are also continuing

efforts to increase consumer involvement in affecting service, and at the same time to train service deliverers to better serve as advocates. We are also concerned with collecting information about service delivery patterns, utilizing existing legislation to improve actual services, and fostering new legislation to meet unsolved problems The easiest way to describe how these objectives are being realized is to give examples of the major current and projected thrusts in the three project sites.

In New York State, the Advocacy Coordinator will continue to work with Home Service Directors to develop needed programs and see that existing services are used. These activities involve an estimated 320 children and their families, including 180 children in the northern rural area. The fifteen Home Service Directors are being trained to fill advocacy roles. Approximately 60 residents of state institutions will be placed in the community as a result of cooperative efforts to train residents and develop community resources. Along with these more direct training efforts, the Advocacy Coordinator is continuing to collect and disseminate data concerning the service needs of the developmentally disabled to be translated into legislative proposals.

In a similar fashion, the Milwaukee Advocacy Coordinator is conducting a fact-finding project, this one to determine problems in the coordination of efforts by various agencies and to develop a consumer-centered, inter-agency network of service. The Milwaukee Coordinator is also promoting the establishment of identification and follow-along programs for approximately 200 "high risk" infants discharged from Neonatal Intensive Care Units in the area. A similar effort will improve service in inner city areas by establishing a casefinding system and a system to insure that resources are available. Major needs in Milwaukee are to develop consumer input to service systems and to coordinate service activity. A Centralized Information and Referral Service and Voluntary Action Center will aid in integrating over 100 developmentally disabled children into community services. That this is indeed a complex undertaking is evidenced by the fact that there are over seven hundred agencies engaged in providing health and welfare services alone.

In San Mateo/Santa Clara Counties, a large part of the emphasis has been placed on collecting information. Data are being collected to show trends in how segments of the population use community resources and how service agencies relate to consumers, with special attention to barriers consumers face when attempting to receive services. Along with these information gathering activities—designed to lead to modification or development of service systems—the Advocacy Coordinator is continuing to conduct advocacy training programs and community organization programs, particularly with consumers who have historically been inactive.

I might also mention some of the activities of the National Advocacy Coordinator. Of course, a major function at the national level is to coordinate and evaluate services in the three regions. We are also looking at how federal legislation is being implemented on a local level and working closely with other groups active in the area of advocacy—for example, the National Association for Retarded Children and the National Center for Law and the Handicapped.

One of the features of the UCP project which might be of special relevance is the UCPA Advocacy Information Center, a developing collection of materials on advocacy. It includes documents published by federal, state, and local public and private agencies; lists of resources available to individuals and groups engaged in

advocacy activities. While this information is primarily for use in the three demonstration projects, it is available to other organizations concerned with the needs of the developmentally disabled.

We feel that this major demonstration project will produce a great deal of information and experience to aid in identifying needs, coordinating service, and developing flexible and workable concepts of advocacy.

PUTTING IT TOGETHER IN OHIO

Parameters, Definitions, and Alternatives for Protective Services

Elsie D. Helsel

BASIC CONCEPTS

Deinstitutionalization and the development of community alternatives for residential care and services are laudable concepts which seem to have the acceptance and enthusiastic endorsement of parents, professionals, state government and the present administration in Washington. The reasons why each group likes the idea of community alternatives are vastly different. Parents feel more comfortable with a model of living somewhat similar to that in their own homes. Professionals think community alternatives are less dehumanizing and have more potential for programs that are developmental. State governments like community placements because they frequently qualify for programs in which state dollars can be matched with federal dollars. HEW officials like community placement because it will help them achieve the presidential initiative of reducing the population of our institutions for the retarded by one-third.

We seem to have an unusual consensus supporting community alternatives. Moreover, no one is happy with the present state of affairs with few alternatives for residential care, old buildings, overcrowding, not enough money, not enough staff, and public apathy except temporarily when a scandal, tragedy, or exposé makes headlines for a few days. However, despite the consensus, just moving from large institutions in the country to small homes in the city isn't going to accomplish miracles—many of the old problems of insufficient funding, inadequate staffing, attitudinal barriers, and inability to meet accreditation standards will still remain. In addition to old problems, some new ones loom on the horizon—problems relating to coordination and monitoring of services for a dispersed population.

As we embrace the philosophy that even the severely mentally and physically handicapped have a right to live as full and normal a life as our knowledge and technology can provide, and as we expand community services, including residential services, so that handicapped individuals can live integrated lives with other citizens in our community, we must face the fact squarely that many of these handicapped individuals cannot make it on their own. They need help in managing themselves and their affairs. This help has to arrive at the exact time it is needed and someone has to be responsible and accountable for seeing that this happens. ***This is what a protective service is all about.***

DEFINITION OF PROTECTIVE SERVICES

Protective Services and Advocacy have become terms with many meanings. Let us define how we are using them at this point in time. Historically protective services for children meant protection from abuse and neglect. For the elderly, where the term protective service has also been used, it meant help with managing money and activities of daily living. Both of these protective activities are time-bound; that is, children grow up, and older persons die. For the severely

handicapped, the term protective services has additional meanings. There are lifelong dependency needs that must not only be monitored but assessed for appropriateness as needs and situations change over a lifetime. The definition we are presently using in Ohio for protective services is:

> Protective services are those services undertaken by a legally authorized and accountable agency on behalf of a client who needs help in managing himself or his affairs. These services may be social or legal in nature and may involve counseling, monitoring, follow-along, program auditing, advocacy, legal intervention, trusteeship, guardianship, and protectorship.

TARGET POPULATIONS

Since mental and physical handicaps come in all shapes, sizes, degrees and combinations, the needs of individuals to be served by protective services vary over a wide continuum. Some individuals, such as the mildly handicapped who are working in the community, need only occasional help with minor problems and decisions. Others who are a little more severely handicapped need help in managing themselves, and/or their affairs, finding appropriate services, and making decisions. Still others need so much help that a full guardianship is necessary in order to keep them from being exploited, neglected or abused.

How to provide a protective system that is flexible enough to respond to these varied needs; that does not overprotect; that allows each individual maximum freedom of choice; that tracks client movements so no one gets lost, yet does not invade privacy or violate confidentiality of records; that is available and accessible to all who need it, yet personal enough to respond to needs on an individual basis—that my friends, was Ohio's dilemma—with many horns.

From the start, we in Ohio felt such a protective service had to have a statutory base if we were going to have accountability. Private agencies and volunteers come and go. Their interests wax and wane. We felt something more permanent was needed. We therefore decided to base our protective service within state government.

We realize full well that in placing this service in state government we have introduced conflicts of interest, bureaucratic red tape, labeling and tracking. However, we feel the advantages of placing this in a state system far outweigh the disadvantages. We also feel confident that we are finding a way to monitor the state system and to work through the problems. We know that the success of any system of services rests heavily on the personalities and attitudes of those giving the service. A dedicated and enthusiastic worker can accomplish miracles—even in state government. The best system in the world can fail to achieve its mark if the people operating it do not believe in it and resist change.

So we have tried to put together a protective system which will respond to the needs of the severely handicapped and their families, and yet will insure that the handicapped are permitted to exercise their full civil and human rights.

BASIC ASSUMPTIONS

In putting the protective system together, we have made certain basic assumptions:

1. The clients will be primarily those individuals so severely handicapped mentally and/or physically that they do indeed need help in managing themselves or their affairs.
2. Community based programs—including suitable alternatives for places to live—should be provided for almost all of the developmentally disabled. The number who cannot live in the community is very small.
3. Since the dependency needs of this group will vary over a wide continuum, the protective system must have a capability for varied response.
4. All human beings are capable of development throughout their lifetime and over a lifetime, therefore, their needs change. Programs and living arrangements should be flexible enough to meet these changing needs.
5. Every human being has inalienable rights—human and civil. For those not capable of exercising these rights, some help must be provided to see that they get their just due and that they are not exploited, abused, or neglected.
6. And finally, we believe that none of us is endowed with God-like powers to know "what is best" for another human being. Consequently we feel that all judgments and decisions concerning those in the protective system should be audited and reviewed regularly by someone else. Each person should have at least two monitors, a protective worker and a personal advocate.

HISTORY

As we conceptualized our system, we tried to learn from the mistakes of the past, remembering that those who do not learn from these mistakes are forced to repeat them.

The need for protective services for those unable to fend for themselves has long been recognized. Families, of course, have been the first line of defense—the primary protectors. As more and more dependent handicapped individuals outlived parents and close family members, problems became more acute. Where property and money were involved, court appointed guardianships were established. However, guardianship alone has not been satisfactory for several reasons. Courts were primarily concerned with the management of money and only secondarily concerned with the welfare of the individual. Even under court monitoring, the ward's funds were frequently manipulated to the benefit of the guardian rather than the ward. If there was no sizable estate to administer, and consequently no money to pay a guardian, few people were interested in assuming such responsibility for another individual without compensation. Where guardians were paid by the state, other problems arose. So guardianship alone has not been the answer.

Institutionalization was another strategy employed by parents to provide lifelong protection for their handicapped children. Superintendents of institutions were then given responsibility for care and custody. With the massive problems inherent in our institutional system, this placed an impossible burden of responsibility on superintendents. It is little wonder that many of our most flagrant instances of the violation of civil and human rights have occurred in institutions.

States have tried various mechanisms for dealing with protective problems for the handicapped. A recent summary compiled by the Division of Mental Retardation in Florida indicated that nine states have special provisions for the handicapped under their guardianship laws: California, Hawaii, Louisiana, Maine,

Minnesota, New Jersey, New York, North Dakota, and Ohio. In some of these states, these are merely new laws on the books. In four of the states—namely, California, Minnesota, New Jersey and Ohio—a protective system accompanies the guardianship. In three other states—Connecticut, Rhode Island and Nebraska—non-judicial mechanisms are evolving which have protective features.

Minnesota

Minnesota has had a guardianship law since 1917 which places responsibility for guardianship on the Commissioner of Public Welfare, who in turn delegates this responsibility to County Welfare Boards in the local communities. County welfare department workers, therefore, are responsible for seeing to it that services and programs are provided to meet the varying needs of the mentally retarded. In the past this guardianship law has had several problems:

1. Parents do not like to give up legal custody of their children to the state in order to get services.
2. Case workers have had a tendency to recommend institutionalization too readily as an easy way out.
3. Constant turnover of caseworkers makes continuity of service difficult.
4. Commitment to the state as mentally deficient restrains the ward for life from exercising his civil rights.

During the past four to five years Minnesota has launched a massive attack on its institutional inadequacies and its dehumanization problems. Some of the problems of the guardianship system have therefore been corrected, and individuals can get community-based services from the state without commitment to guardianship. This is a model that certainly bears investigation.

California

With the establishment in California of the Regional Center Program in 1965 and the Personal Guardianship Law in 1968, California has made giant steps in the provision of protective services for its retarded. The Regional Center Law provides for the following services by Regional Centers: (1) diagnosis; (2) counseling on a continuing basis for the retarded and his family to assist them in locating and using suitable community services; (3) vendor payments to agencies; (4) provision for contracting with private agencies for services, including residential services, with funds provided by the state; (5) maintenance of a case registry and individual case records; (6) systematic follow-up; (7) assistance with state hospital placement where this is an appropriate alternative; (8) responsibility to call the attention of community agencies to unmet needs and to stimulate and assist communities in the development of needed services.

The Public Guardianship Act passed in 1968 provides that the Director of Public Health may be nominated, in writing, by a parent, friend, relative or guardian of the mentally retarded person or by the mentally retarded person himself, to serve as guardian or successor guardian. An annual review is required, in writing, for all individuals under guardianship. On paper and in practice, the California program has good potential. Not that there are no problems with the California system—not

enough money, not enough residential facilities, not enough staff. However, progress is being made.

New Jersey

New Jersey has approached the problem of guardianship for the retardate over the age of 21 in another way. New Jersey law now requires that all mentally retarded persons receiving services from the Division of Mental Retardation who are about to become 21 years of age be examined to decide whether they need a guardian. The Commissioner or Division Director has assigned the responsibilty of deciding who needs a guardian to the heads of "service units." If the individual client is in a New Jersey institution, this would be the superintendent. If he is in a day care center, it would be the director. If it is decided that the client is mentally deficient and in need of a guardian, the head of the service unit will notify the natural parents or next of kin and will encourage them to obtain legal guardianship. If the parent does not want to undertake legal guardianship, he is asked to state this in writing to the Division. The Division Director will then perform "guardianship services" for the mentally deficient person. This type of guardianship is "guardianship of the person" and deals only with the person and not with his property. The case worker offering guardianship services for the Division will ordinarily consult with the parents and other close relatives before making decisions for the mentally deficient person. If the parents or relatives are not available, the case worker will make his own decision. At present there are 40 case workers assigned to this service. In addition, there are eight case workers assigned specifically to guardianship clients. One of the problems that has arisen in the implementation of this law is the long delay in the courts for guardianship proceedings. There has also been considerable expense involved in the securing of the guardianship by natural parents, with costs running from $200 to $700.

Connecticut

There is no public guardianship law in Connecticut, but the provision of protective service is allowed for under an authorization in another law stating that it is the moral responsibility of the Bureau of Mental Retardation to look after the best interests of the mentally retarded within the state. Connecticut's program for the mentally retarded has been regionalized and the protective services are offered through the twelve Regional Centers. The Connecticut Bureau of Mental Retardation can purchase service or contract with other public and voluntary agencies for service. Connecticut has computerized tracking on all individuals in the state who are enrolled in any specialized service for the mentally retarded. This includes special classes in schools, clinics, vocational rehabilitation agencies, and welfare departments.

Rhode Island

In 1971 Rhode Island began a follow-along service for the mentally retarded in the community. Although the social workers assigned to this service are based in the Regional Centers, clients are not limited to Center clients. Workers serve as advocates and interventionists for any individual brought to their attention. They

deal with the presented problems, inform the clients about available services, and provide supportive counseling to clients and their families to help them rationally assess the situation and achieve optimum use of services throughout the client's life cycle.

Nebraska

Nebraska too has no special guardianship law but it is in the process of setting up a statewide Citizen Advocacy Program which is described elsewhere in this monograph.

OHIO'S PROTECTIVE SERVICE SYSTEM

Ohio has had an interest in and a concern for protective services for the mentally retarded for over a decade.

The 1963–1965 "Report of the Citizens Committee on Comprehensive Mental Health Planning" stated:

> A protective service should be established to assume protection throughout the lifespan of the mentally retarded.

This recommendation became part of the MR Plan: "Mental Retardation, The Ohio Plan–1966." As this plan moved into its implementation phase, a Task Force on Protective Service and Public Guardianship was appointed. As is frequently the case when a good idea gets translated into an action program, the right people were in the right place at the right time. Funds were secured from United Cerebral Palsy for calling a national conference at New Kensington, Pennsylvania, in 1966 in order to pull together all existing knowledge on protective services. Invited to that conference were individuals from children's protective service agencies, protective services for the aging, the Minnesota Department of Public Welfare, the guardianship program in New Jersey, California's Guardianship and Regional Center program, Connecticut's Regional Center program, the President's Committee on Mental Retardation, the National Association for Retarded Citizens, and United Cerebral Palsy.

The purposes of this conference were:

1. To define the problems and needs in the area of protective services for the handicapped.
2. To collect information on on-going programs.
3. To formulate general principles and list specific actions that a protective service should be willing and able to undertake.
4. To incorporate the principles and specific actions into a plan.

A UCPA publication from this conference ("Proceedings of the Conference on Protective Services and Supervision for the Handicapped") summarized and evaluated all protective programs at that time. A spin-off benefit of this conference came when Dr. Wolf Wolfensberger substituted for the PCMR representative Dr. Robert Kugel. Dr. Wolfensberger learned about protective services and was stimulated to go home and develop his concept of Citizen Advocacy.

Tho Ohio representatives at the conference–the late Professor Herschel Nisonger, Director, AAMD Division of Special Studies; Dr. Roger Gove, former

Director of the Division of MR and DD; and Dr. Elsie Helsel, Chairwoman, UCPA's Program Services Committee—went back to Ohio and drafted a grant proposal for a pilot project on protective services which was funded in 1968. The primary purpose of this proposal was to get operational experience based on the information gained at the New Kensington Conference.

Three pilot projects were established and much information was gleaned from their operation. At the end of the grant year, Dr. Gove scrounged money from his budget to keep the operations on-going.

As a result of the positive experience gained in the project, it was decided to seek a legislative legal base for the protective program. A Protective Service and Public Guardianship Committee of the Ohio Association for Retarded Children wrote the present law and lobbied for its passage. The law (H.B. 290) provided for a statewide protective service/public guardianship program with the following characteristics:

1. Individuals may enter through voluntary enrollment or court commitment.
2. The Director of the Division of Mental Retardation and Developmental Disabilities may accept public guardianship of the person.
3. Before entering the system, each client must have a comprehensive evaluation.
4. The protective service agency may provide protectorship, trusteeship, and guardianship.
5. The state may provide protective services itself or may contract for such services.
6. The Division must provide in writing at least once a year a review of the physical, mental, and social condition of individuals for whom it is acting as guardian, trustee, or protector

There are no filing fees associated with either the public guardianship or protective services programs.

The bill became law in April, 1972. Regulations and guidelines have been written, and almost forty workers have been hired and trained. A decision was made that during the initial phase, the protective service would be provided by the Division of Mental Retardation and Developmental Disabilities rather than contracted out. The person responsible at the Division level for the service is an Administrator of Protective Service and Public Guardianship. The protective service workers in the field are based in the Division's district offices, but report directly to the Administrator. All such workers have no other duties within the Division. The administrative unit is completely separate from other units in the Division of Mental Retardation, with the administrator reporting directly to the Commissioner of the Division of Mental Retardation and Developmental Disabilities. The idea behind this arrangement is to keep the "monitoring," "program auditing," and "advocating" functions of the protective service workers separate from the "provider" functions of the Division of Mental Retardation and Developmental Disabilities.

How to Get Into the System

Persons can get into the protective system in various ways:

1. By requests from the developmentally disabled person himself.
2. By parental or relative request.
3. By referral from the District Office of the Division of MR and DD.
4. By public agency referral.
5. By voluntary agency referral.
6. By protective service worker referral.
7. By court appointment.

Probate courts of Ohio were very cooperative in working with the groups seeking passage of this law. In addition to assigning guardianships directly to the Division of Mental Retardation and Developmental Disabilities, the courts are using the resource of the protective service workers in helping them make decisions concerning assigning guardianships, terminating guardianships, and managing guardianships. Plans are underway to train a group of young lawyers in the state to work with the courts and with the protective services system.

For interested handicapped individuals, parents, or other friends or relatives who wish to enroll in the system, the procedure is as follows. A letter of request is sent to the Director of the Division of Mental Retardation and Developmental Disabilities or to the administrator of the protective services program. A protective service worker is assigned and background information is assembled. This includes a comprehensive evaluation, as well as general information concerning the needs of the client, his family situation, his financial situation, and so forth. The protective service worker makes an initial needs appraisal for the individual seeking entrance. Based on this information, the decision is made whether to accept the individual into the protective system. If he is accepted, he and his family are notified in writing. At time of enrollment in this system, the individual and his family are informed concerning the procedure for terminating protective services if they so wish.

There are two ways to get into the protective service system through the courts—through a regularly established guardianship, and through a successor guardianship requested by parents in their wills. The Division of Mental Retardation and Developmental Disabilities can, under the Ohio law, serve as the guardian in both of these instances. Increasingly, protective service workers have been called in by the probate courts before such guardianships are assigned. In the future, if inappropriate guardianships are requested, protective workers will hopefully serve as representatives of the developmentally disabled and advise the courts in their best interests. It should be noted that in both the pilot project and the protective services program to date, very few guardianships have been requested. Most problems have been handled through advocacy and intervention without the necessity for such absolute control as a guardianship represents. Undergirding the philosophy of protective service is the use of the least amount of control appropriate in each situation and the involvement of the client himself in the decision-making process to the greatest degree possible.

Responsibilities of a Protective Services Worker

As the service is presently operating, the basic responsibilities of protective workers are:

1. Outreach—letting parents and agencies know what the services and procedures are, developing relationships with parents and prospective clients, furthering public education, scanning special services roles, and intervening in crises.
2. Counseling—talking with parents and clients in order to solve minor problems, getting insights into major voiced and unvoiced problems, determining what the present or future needs and problems are, helping families start to plan ahead, and counseling "significant" others.
3. Needs Appraisal—getting a first hand "eyeball" or informal impression of what the service needs may be in order to make more appropriate referrals.
4. Referral for service and coordination with case managers and other agencies.
5. Follow-up and follow-along.
6. Monitoring.
7. Program auditing.
8. Advocacy for rights such as education, social security, welfare, Medicaid, the new SSI program, and Crippled Children's services.
9. Legal intervention—intervening in cases of neglect, abuse, or inability to cope, or in cases of problems with inadequate guardians.
10. Services as a trustee, protector, or guardian.
11. Preparing written annual reports on the physical, mental, social, and educational status of each client in order to fulfill the mandate of an annual report in the law.
12. Capability for 24-hour response.

Developmental Disabilities funding has paid for on-going in-service training courses for protective service workers. These courses are conducted by the University Affiliated Facility at Ohio State University in Columbus. DDA funds are also paying for a staff position within the Division of Mental Retardation to develop a computerized tracking system for the protective service system as well as for other client services of the department. Finally DDA funds are being allocated for a legal back-up and intervention system in the state protective services system.

The Personal Advocacy System

Enthusiastic as we are about the potential of our protective services system, we feel that it needs a watchdog. Again using DDA funding, we are putting in place a system completely separate from the official tax-supported system in order not only to monitor the protective service system but to provide a more personalized, individualized advocacy relationship.

Volunteer personal advocates are being recruited, matched, trained, supervised, and backed up with trained staff. However, they will be free to act independently on behalf of their clients. DDA funds are supporting a State Coordinator of

Personal Advocacy who works under an incorporated consortium, Ohio Developmental Disabilities, Inc., composed of representatives from the Epilepsy Foundation of America, the Ohio Association for Retarded Citizens, and the United Cerebral Palsy Association of Ohio.

The local coordinating groups for personal advocacy activities will be the reactivated district Citizens' Committees. These are voluntary bodies which functioned during the 1963-1965 period when statewide planning for mental retardation was underway. They will now have two major foci of activity—the development of the personal advocacy system and grassroots planning for residential care.

Patterned after the Nebraska Citizen Advocacy Program, the activities of the personal advocates will include the following:

1. Being a friend.
2. Knowing the client's personal needs and wishes, his program needs, and his program prescription.
3. Knowing community resources.
4. Raising questions concerning the appropriateness of the client's program.
5. Keeping in touch with the client's professional helpers.
6. Being acquainted with the client's neighbors, landlady, shopkeepers, and policemen in the area.
7. Keeping promises made to the client.
8. Keeping commitments made to the Advocacy Consultants.
9. Attending training and refresher sessions.

It should be pointed out that there are no money commitments from advocate to client. There is a small slush fund to pay for sundries, tickets, fees, and other small expenses that might arise in connection with advocacy activity.

Conclusion

Although the protective services system is in place statewide, it is a fragile new system. Even as we attempt to work through our "growing pains," we realize that at this point in time, we must maintain a flexible posture. There is no "one" perfect system that will protect the human and civil rights of all developmentally disabled individuals. We do know that protective mechanisms of the past such as extended families, court appointed guardians, and institutions are no longer sufficient for the needs of today, especially as we move forward with our deinstitutionization initiative.

We must continue to rework the system we have fashioned so that it guarantees entitlements, providing opportunities for all handicapped individuals to develop to their fullest potential and "to live out their lives with respect and dignity, side by side in communities where each man is his brother's keeper (Blatt, 1973)."

References

Blatt, B. Changing institutions and the development of community alternatives. Paper presented at the meeting of the American Association on Mental Deficiency, Atlanta, May 27-June 1, 1973.

PROTECTIVE SERVICE AND PUBLIC GUARDIANSHIP IN OHIO

Phyllis Emory and William H. Parks

While many retarded individuals will develop to the point of independent living and be able to manage their own affairs, there are many other mentally retarded and developmentally disabled children and adults throughout Ohio who need assistance in gaining their rights as citizens of their community and state. Of this number, the large majority can remain out of an institution and can live and function in the community if there is a formalized system operating and available to them during the crisis points in their lifetimes.

The need for protective service and guardianship for the disabled person has long been recognized by parents of the retarded and other developmentally disabled persons. Today, with an increasing emphasis on lifetime community living as the primary goal in serving the retarded, this need for protective service becomes even more acute.

Protective services are those services and activities which are undertaken by an individual or agency on behalf of other individuals who are not fully able to act for themselves. These protective services or activities are directed toward the individual's welfare in a systematic manner, are backed up by legal sanctions, and are carried out through case management techniques.

A demonstration grant was sought and received from Social and Rehabilitation Services, and the United States Department of Health, Education and Welfare in 1968-1969 by the Ohio Citizens Committee on Mental Retardation Planning and Implementation, with the support and assistance of the Division of Mental Retardation and Developmental Disabilities. We were aware of the limited knowledge and experience in the provision of such services. The pilot demonstration in three counties clearly demonstrated the need for protective services and public guardianship. From this demonstration project and the supporting technical advisory committee, a plan and needed information for the passage of legislation was developed. Also, an "Information Manual for the Protective Service and Public Guardianship Project" was prepared.

Amended House Bill 290, authorizing the Division of Mental Retardation and Developmental Disabilities to establish the Office of Protective Service and Public Guardianship, became effective on March 23, 1972. At that time, the position of Administrator of the Office of Protective Service and Public Guardianship was created, and a Central Office staff member researched and drafted the regulations for the operation of the state-wide system of service and the information necessary for writing the Executive Order. The purpose of Amemded House Bill 290 was to establish protective service and public guardianship for mentally retarded and other developmentally disabled individials in Ohio. An initial field worker staff of four members was hired by September, 1972, and statewide service delivery began.

To facilitate the provision of protective services to the individual in his community, the Division of Mental Retardation and Developmental Disabilities has established twelve district offices. Case Management and Protective Service Workers are being assigned to the district offices. Each district office relates to an institution, and a paramount responsibility is to screen admissions so that only those in need of institutional treatment are admitted and to monitor the residents

so that they are returned to the community without undue delay to an appropriate comprehensive service which must include foster home/private home, training and/or employment. A second area of responsibility is to maintain an appropriate and stimulating environment to develop the potentials of those individuals who presently reside in the community so that future institutional care may not be required. Case Management and Protective Service Workers emphasize and stimulate the provision of comprehensive community services and facilities, together with existing generic agencies, and assist in developing additional services for mentally retarded and developmentally disabled individuals.

GENERAL PROGRAM DESCRIPTION

The planning and programming efforts of the Division of Mental Retardation and Developmental Disabilities have been decentralized to twelve District Offices. Each District Office, when fully operative, will have a District Director and a professional staff of Case Managers and Protective Service Workers. Responsibilities for each category of worker are outlined with respect to the type and kind of service to be rendered to the mentally retarded and developmentally disabled individual. In general, Case Management Workers are responsible for a broad scope of duties, from initial intake to referral and coordination of client services. Protective Service Workers are primarily concerned with the client's interest and rights and serve the individual as a personal advocate as sanctioned by law. Protective Service provided to the individual may range from intermittent guidance for the individual who needs minimal help in daily living to the establishment of a full guardianship.

Provisions within H.B. 290 establish the Division of Mental Retardation and Developmental Disabilities as the legal state agency with responsibility and authority to implement and administer protective services to mentally retarded and/or developmentally disabled individuals within the State. Moreover, within the Division of Mental Retardation and Developmental Disabilities, an Office of Protective Service and Public Guardianship is established to manage the statewide protective services program. That Office, as authorized in the bill and backed by legal sanctions, may intervene on behalf of mentally retarded and developmentally disabled persons when care and management of the individual is required.

Program Rationale

The care and management needs of mentally retarded and developmentally disabled persons have served as the rationale for developing the program. Too frequently these individuals have become victims of society. Intellectually and/or physically incapable of managing their own affairs and lacking private individuals to protect their interests, the mentally retarded and developmentally disabled have been neglected and exploited financially, physically, and emotionally. Yet, they have inalienable rights to decent standards of living, personal concern, and enriching opportunities. These services are being provided for children and adults. An estimated 98 percent of the mentally and developmentally disabled meet the eligibility requirements as social services recipients.

The severity of mental and physical handicaps vary in degree significantly. For those mildly handicapped persons who may be employed in the community, only minimal guidance and counseling may be necessary. Persons whose limitations are

more severe may require extensive help in managing their affairs. For some, a full-blown legal instrument, such as guardianship, will be necessary to protect them from exploitation and abuse. Protective Service is designed to offer a continuum of service to meet the wide range of needs of mentally retarded and developmentally disabled persons.

A modest estimate of the number of people who can be served through the Protective Service program is 40,000 adults and 20,000 children. This figure represents contributions from all 88 counties in the state and consists of mentally retarded and developmentally disabled children and adults with measured I.Q.s generally, but not limited to, 50 or below. The major proportion of these individuals are classified as moderately, severely, and profoundly retarded and disabled and would require substantial care and management services in daily living. Provisions within H.B. 290 now make it possible through the Protective Service delivery system to reach those persons who are most in need of this program and who previously have been denied substantive care and management assistance.

Case Management is defined as an organized system of establishing a relationship with a mentally retarded or other disabled individual and his family in order to: (1) identify the individual's special needs (2) make arrangements to meet those needs through appropriate programs and services; and (3) evaluate the results of those services and programs by means of regular, systematic contacts with the individual. Required, in addition, is the capability of responding to changes in his status on a twenty-four hour, seven-day-a-week basis. Case management services will be provided to a mentally retarded or other developmentally disabled person regardless of age or degree of disability. It is estimated that approximately 38,000 individuals may be in need of case management services at any given moment in time.

Program Goals

Recognizing the needs of mentally retarded and developmentally disabled individuals, the Division of Mental Retardation and Developmental Disabilities, through its Office of Protective Service and Public Guardianship, prepared the following general and specific goals to give meaning and direction to the proposed program:

1. General Goals
   a. To protect mentally retarded and developmentally disabled individuals from societal neglect, exploitation, and abuse.
   b. To enhance the lives of mentally retarded and developmentally disabled individuals through development of their personal potentials.

2. Specific Goals
   a. Aggressive identification of the mentally retarded and developmentally disabled.
   b. Provision of counseling as indicated.
   c. Coordination of services for individuals, i.e., income maintenance, placement program, and so on.
   d. Follow-along, including Public Guardianship and Trusteeship.
   e. Public advocacy of the mentally retarded and developmentally disabled.

The General Program

The responsibility for seeing that every mentally retarded and developmentally disabled individual in the District has an adequate program lies with the Case Management and Protective Service system. The Protective Service Workers are housed in the District Offices but have no direct responsibilities to the District Administrators. They report directly to the Administrator of Protective Service and Public Guardianship in the Central Office of the Division of Mental Retardation and Developmental Disabilities. The Protective Service units are administratively separate from the other District Office departments in order to eliminate, in so far as possible, conflict of interest between "monitoring" functions and "provider" functions. In this context, case management services constitute one of the services "provided" by the Division of Mental Retardation and Developmental Disabilities.

Protective Service Workers are engaged in such activities as monitoring, counseling, tracking, appraising, and advocating service for individuals who need help in managing themselves and/or their affairs—either through agreements or court determination. Advocacy may be of the personal service type, whereby one Protective Service Worker assumes responsibilities for looking after, as if they were his own, the interests, rights, and personal needs of a mentally retarded or developmentally disabled individual. The Guardianship and Trusteeship functions require gathering substantiating evidence for probate court appointment and subsequent accountability to the court.

A vital component of the system must be that it not over-protect, and that it allow the individuals served maximum self-reliance and freedom of choice. It must also guard against usurping the individual's right to manage his own affairs if he is capable. Hence, the delivery system has written into its policies and procedures the requirement for comprehensive evaluations of all clients in order to establish need, and a complete section on how service may be terminated at either the individual's or agency's request.

Total planning includes placement of Workers in field locations which will be readily accessible to the individuals requiring service. The number of staff necessary in each field office will be determined from the populations to be served within the district. The Protective Service Worker travels to the individual requiring the Service, advises the individual of the kinds and the extent of the Service, and makes arrangements to obtain comprehensive evaluations and other necessary information. In this regard, Protective Service Workers will be on twenty-four hour call. The Administrator's and the Assistant Administrator's telephones are open for emergency calls at all times. A call to either of these numbers generates a call to the Worker in that district, who will respond to the need. The Protective Service system must be responsive to both crisis and routine need. The Office of Protective Service and Public Guardianship can be a well-coordinated yet flexible and highly responsive system to meet the needs of the mentally retarded and developmentally disabled. An integral part of the delivery system is the availability of Case Management Workers within the field office, who provide additional resources and manpower to help Protective Service Workers with individuals they are assisting.

PROCEDURES FOR IMPLEMENTING CASE MANAGEMENT AND PROTECTIVE SERVICE IN THE COMMUNITY

The professional staff within the District Offices consists of two main types of workers:

1. Case Management Workers—those personnel whose major responsibilities are case management services and who provide an organized system of social service techniques for clients, including intake, diagnosis, evaluation, programming, referral to appropriate services, and coordination of generic services which may serve a client. They are also responsible for developing and finding appropriate homes for the disabled in the community.
2. Protective Service Workers—those personnel whose major responsibilities are protective services, who monitor an individual client with regard to his interests, rights, and personal needs, and who serve as statutory advocates of mentally retarded and developmentally disabled clients.

The two types of workers operate by the following procedures:

1. The identification of clients and the initiation of Protective Service follow the procedural plan as outlined in the Regulations for Protective Service and Public Guardianship. The provision of Protective Service for a mentally retarded or developmentally disabled individual may be initiated by:

   a. An individual who believes he is in need of Protective Service
   b. A parent or other relative
   c. Any other interested person acting in the interest of the individual
   d. Other agencies
   e. The Division of Mental Retardation and Developmental Disabilities
   f. The probate court

   Within this framework for obtaining clients, the Division of Mental Retardation and Developmental Disabilities reaches out into the communities served by its District Offices and locates potential clients who are not now known to public and private social agencies. This undertaking enlists the services of the professional staff and indigenous workers as possible additions to District Offices.

2. The counseling of clients is an integral role played by both Case Management Workers and Protective Service Workers. In the intake process, preliminary contact with the client is made by a Case Management or Protective Service Worker. Subsequent to the client's placement in a program commensurate with his needs, counseling by a Protective Service Worker is provided. The type and amount of counseling varies in relation to the need. Types of counseling may include supportive counseling, information giving, and family counseling as they may be constructively conducted by the Protective Service Worker. In general, counseling may be informal and spontaneous, conducted wherever the client feels most comfortable and best able to relate to his Protective Service Worker his present problems.

3. The monitoring of services to meet specific needs of clients is the responsibility of the Protective Service Worker. Case Management Workers housed within the District Office are able to supply background information on the client when it is relevant to the particular case in point. The coordination of such services as income maintenance, vocational placement, foster home placement, and recreational and educational program placement requires a thorough knowledge of the client and the activities in which he is or will be a participant.

4. Tracking and follow-along of clients is a major responsibility of the Protective Service Worker. Up-to-date records are kept for each client on data processing print-out sheets. Feeding data into a computer allows for a concise and systematic tracking of clients and for immediate retrieval of information to be used in the counseling and guidance process.

5. Amended H.B. 290 gives legal sanction to the Office of Protective Service and Public Guardianship to intervene on behalf of the client's rights, interests, and personal needs. That Office, through legal documents or by written contract with the client or his family, may become the statutory Protector of the mentally retarded or developmentally disabled individual. The Regulations for Protective Service and Public Guardianship indicate that Guardianship and/or Trusteeship shall be accomplished by means of a referral by the Office of Protective Service and Public Guardianship to the Probate Court for appointment, with such supporting evidence as is required.

6. Public advocacy of the mentally retarded and developmentally disabled client rests not only with the immediate Protective Service Worker but with the Division of Mental Retardation and Developmental Disabilities, its sections, and constituents. Within this framework, the client may be apprised of his rights and privileges as these are written into law and so made enforceable.

OUTCOME INDICATORS

The Protective Service and Public Guardianship program must not only monitor individual needs, rights and interests of the developmentally disabled, but also monitor itself and in addition, be overseen by a volunteer component of personal advocates. Indicators of the effectiveness of the program are:

1. The number of clients whose lives were changed in a positive direction, who were enabled to function more independently in the community.
   a. Percent of clients we were able to maintain successfully in the community.
   b. Percent of cases in which we were able to intervene legally to protect clients from societal exploitation and also to assist the community's authoritative bodies, particularly in the judicial system, to make more appropriate dispositions of the mentally retarded and the developmentally disabled.
   c. Number of cases resolved with less judicial involvement than previously needed.

   d. Number of cases in which we were able to provide appropriate supervision to relieve individual and community anxiety.
2. Number of programs we were able to develop to serve the unmet needs of mentally retarded and developmentally disabled individuals.
3. Number of cases served.
4. Number of individuals returned from institutions to the community using the mechanisms of Protective Service and Public Guardianship.
5. Number of individuals maintained in the community without commitment to institutions.
6. Reduction of the institution population resulting in increased ability to provide quality care for those persons in residence.
7. Services rendered, as evaluated by:
   a. The client
   b. The Workers themselves
   c. Referring or interested agencies.

A PROGRESS REPORT

Although the Ohio Protective Service and Public Guardianship program is still evolving, it is possible to offer some information about what has happened from June, 1972, when the program began, to the early months of 1974. The Office of Protective Service and Public Guardianship, reporting directly to the Commissioner, is an independent unit within the Division of Mental Retardation and Developmental Disabilities. Current plans call for some revision—an emphasis on decentralization, a closer relationship between protective services and case management, and an independent and district-based volunteer personal advocacy system. Thus, we hope to do more than we can presently do by having both protective services and citizen advocacy responsible for insuring the rights of the developmentally disabled.

The current staff of the Office of Protective Service and Public Guardianship includes a central office staff and protective service representatives in each of 12 districts. The central office staff consists of an admisistrator, an assistant administrator, an administrative assistant, and two clerk-typists. There are now 32 protective service representatives, with from one to five in each district depending on population and need. There are also two area coordinators, each of whom administers the program in two populous districts which require more service. The total staff, then, consists of 39 people. The protective service workers themselves come from varied backgrounds and were not necessarily trained in mental retardation. Seven have Master's Degrees, while 25 have Bachelor's Degrees. A large number of them, whatever their academic training, have had experience as teachers and professionals in various social service programs. Table 1 presents an update report (as of May 28, 1974) on the activities of the Office. Out of a total of 2,327 clients, 198 across the state have already entered into voluntary protectorship agreements. Fifty-three now have state guardianship relationships which are geared toward protecting person rather than property. In six cases, there was a need for a combined guardianship-trusteeship relationship which would protect both person and property, and in four cases, testamentary guardianships specified in the wills of parents or legal guardians were processed through probate court along with the

Classification	Number of Clients
Protectorship	198
Guardianship	53
Testamentary Guardianship	4
Guardianship-Trusteeship	6
Trusteeship	2
Closed Cases	53
Closed--Not Applicable	6
Inactive Cases	206
Open Cases	1,093
Referrals	706
TOTAL	2,327

Table 1.

The Statuses of Protective Service and Public Guardianship Cases in Ohio as of March 28, 1974.

wills. Only two trusteeships, which establish trustees for property up to the amount of $3000, have been established. There is no sign in these figures that the more formal guardianships and trusteeships are being overused.

Although it is expected that many more protectorships will develop, the Office of Protective Service and Public Guardianship is arranging for a number of services outside of the more formal agreements between worker and client. The category labeled "Referrals" contains a large number of new clients whose comprehensive evaluations have not yet been completed. A few of the clients referred to the Office must be closed as "Not Applicable" because their problems are mental illness, alcoholism, or some other disability which does not fall under the province of mental retardation and developmental disabilities. Other cases are closed when the client indicates that he does not desire service or moves from the state and is absent for a period of five years. Some clients in the "Inactive" category have moved from the state but have not been absent long enough to be closed. Many others in the inactive category have been helped. For example, often the primary need expressed in requesting services is a temporary one such as the need for a home or residential placement.

If the need for an appropriate placement is the sole or major need, the case might be considered inactive once the placement is made. Many other clients who are still carried as active cases might have been helped to obtain appropriate services or placements but still can benefit from other types of support from protective services.

Taking all of this into account, it is clear that the protective service representatives are not actively serving as many clients as their caseloads would suggest. Although the caseload has fluctuated from month to month, the caseload as of March, 1974, averaged 73 (2,336 clients and 32 protective service representatives). Taking the above considerations into account, we see that closed cases, and to a lesser extent inactive cases, do not require as much attention. However, the caseload is still quite large, and it takes a great deal of time to evaluate needs for protectorships, guardianships, and other types of relationships.

Protective service is a major undertaking which requires a large staff. The budget for the Office of Protective Service and Public Guardianship is currently $1,200,000. A major expenditure, of course, is staff salaries, with the average protective service representative earning approximately $10,000 per year. Due to the nature of protective services, travel budgets are large, with the average protective service representative travelling 1450 miles per month.

Although program revisions are on the horizon, we feel that the Protective Service and Public Guardianship program is already filling important gaps in Ohio's services for the developmentally disabled. We hope to be able to evaluate the program more formally as it evolves.

PROTECTING THE CIVIL AND HUMAN RIGHTS OF THE DEVELOPMENTALLY DISABLED

Michael Kindred

My role at this conference is, I believe, that of the spoiler. You have heard advocates of protective services for two days. I intend to provide a critique of protective services, and the Ohio protective services system in particular, from a legal and policy perspective. I will not talk about citizen advocacy as much as about protective services because it is protective services and guardianship that raise the most serious problems. Although the Ohio system may differ somewhat from models being developed in other states, it is similar in some essential respects to other state guardianship and protective service programs, and more importantly, it may be seen as a model by other states developing new programs. It is very important to examine the Ohio law critically because the potential of the concept of protective services, for both good and bad, is enormous.

Before I really begin, I would like to ask how many of you have retarded children. Those of you who do not might try to project yourself into the role: If you have a retarded child, would you want some sort of protective service system available? Would you buy the Ohio statute if you wanted a law to "protect" your retarded child? And one final question, the most important: How many of you would like to have a protector for yourself?

Our basic task is to put ourselves in a position to critically evaluate the bill, at first by asking this: If the bill did not say "for the mentally retarded," would we find it acceptable? If the bill allowed for the appointment of a protective service worker for any citizen, not just the sub-category of mentally retarded or developmentally disabled citizens, would we find the legislation acceptable? My answer to that is, "No way." Of course, some might say that they would not mind having a protector now and then, but it seems to me that a basic premise of our society is that we do not set up relationships in which someone is someone else's protector and controller. If that bill were to be applicable to all of us, we would either reject it or tighten it up considerably so that there were safeguards, so that it was only used in the proper situations after adequate investigation. If we find it unacceptable when we are the targets, why do we find it acceptable when it is restricted to the developmentally disabled?

Singling out the mentally retarded or developmentally disabled for application of protective services is an improper use of classification schemes, for those terms do not describe the group we are aiming at. On one hand, we are not aiming at all mentally retarded persons, only those who are substantially handicapped in their ability to negotiate the community. At the same time, our target group should logically contain people who are not mentally retarded but who have similar needs for protection and control as those of substantially handicapped mentally retarded individuals. In trying to determine "why the mentally retarded," perhaps we need to ask how we regard the mentally retarded. Surely they have all of the rights and liberties of other citizens—indeed of all human beings. This thought seems simple enough, but our society has developed about sixty different ways to throw away the retarded and restrict their right to be full members of society. Many times we as individuals have a hard time acting on the premise that retarded persons are as truly and fully human beings as every one of us. Let me now examine protective services

generally in two contexts: (1) guardianship and control systems, generally; and (2) protection of persons' rights. I will then deal specifically with the Ohio Protective Services System.

GUARDIANSHIP AND CONTROL

Protective services must be seen in the context of the whole guardianship structure. As most of you know, guardianship law in general has tended to be property-oriented rather than oriented toward personal decision-making. Guardianship laws originally were designed to prevent family fortunes from being squandered when people are judged incompetent of managing property themselves. As public institutions for the mentally retarded and mentally ill developed, the concept of guardianship was adapted for institutional use. When someone is institutionalized, the superintendent or someone in the system is made a guardian, increasing the institution's control over the decisions which the person might need to make. In either case, the concept of guardianship is a concept of control. The basic assumption is that some people are not able to make rational decisions and therefore need substitute decision-makers and controllers.

Recently the concept of guardianship has been extended further in the form of what we call state guardianship. The State or an officer of the State can be appointed guardian for a person, even if the person is not in an institution. The earliest example was the guardianship system developed in Minnesota, where, very simply, an officer of the State could be appointed the guardian of a mentally retarded individual. The Minnesota system appeared to offer a solution to parents and family members who worried about what would happen to their children after their death if they were living in the community. The Minnesota Association for Retarded Children urged that all retarded individuals be enrolled in the state guardianship system, even where they already had individual guardians. The Minnesota state guardianship system has been heavily used, and Professor Robert Levy has suggested that it has been overused and has contributed to overuse of institutionalization as a solution to practical management problems. When California started to develop a guardianship system, people had begun to be concerned about the control that the concept of guardianship implied. The recognition that guardianship provides a great deal of control and takes away a great many individual rights led to a search for more limited forms of guardianship in which a substitute decision-maker would not take over all decision-making.

It is safe to say that the Ohio protective services system developed out of this concern. The Ohio act, like the Minnesota system, allows for full-blown state guardianship by the Division of Mental Retardation. In this sense, it is nothing new. However, it also created a strange new animal called a Protector. "Protectorship" is a term intended to represent a limited form of control, but the fact remains that it arose from a control orientation and that it is a modification of the guardianship concept. There is a clear danger in the very fact that "a protective service relationship" is such a pleasant-sounding phrase. The phrase may sound so attractive, in fact, that we run the risk of using the new arrangement with less hesitation and fewer precautions than we use guardianship arrangements. What can we lose in establishing a protectorship? The retarded person is likely to say, "Sure, I'll take a protector." But, at the same time, we must suspect that the new arrangement has some teeth; after all, it arose out of a control orientation.

Which brings us back to the issue of control. Justice Brandeis once said that the most fundamental right is the right to be let alone, to tell other people to keep their hands off us and not try to make decisions for us. This right is fundamental in our society; it is a right which extends to the mentally retarded if they are full members of our citizenry. Let me give an example. In talking to protective service workers in Ohio, I heard about an old person who moved into a run-down hotel and ate candy bars three meals a day. From my perspective as critic, I was not sure that that person needed protection, not if it interfered with his right to be left alone. I would have to be convinced of a compelling need for control, whether the control takes the form of a legal guardianship or a protective service relationship.

PROTECTION OF RIGHTS

We can also profit from examining protective services within the context of protecting people's rights. It is extraordinarily difficult to protect people's rights. Protecting rights does not mean protecting people by controlling them—e.g., by insuring that they eat the right foods. Let me offer two examples, the first dealing with sterilization. In Ohio, there is no statute which mentions sterilization. In the absence of legal authority, one might think that it is far-fetched for anyone to sterilize anyone else without their consent. However, because of pressure to permit sterilization, an ingenious system developed over time. A parent would go to an agency for help; the agency and the parent would go to a doctor and then to the court. In one such case, the parent, the agency, the doctor, and the judge met, along with a lawyer appointed to act as guardian for the girl whom they wanted to sterilize. After hearing that everyone was for it, the judge said, "I have the power to do whatever is in the best interest of children or incompetents brought before my court. Because this person is a child and is incompetent, I hereby authorize sterilization." The crucial point is that all of the participants were responsible people acting as protectors. In the actual case, the girl decided in a few years that she did not like being sterilized and sued the participants in federal court for three million dollars. Although the orginal judge argued that he had the inherent power to make such a decision, the federal court ruled against him, and the whole episode more or less stopped sterilization in Ohio. At least I thought so, until I visited Cleveland General Hospital and talked with a group of people on the Child Abuse Team. To my surprise, their questions to me largely centered on sterilization, and it finally came out that they had been sterilizing teenage girls at parents' requests for a year—without any intervention by the courts. This is the Child Abuse Team, composed of people who were supposed to be protecting children's rights and who knew about the federal court case!

The question I would raise is whether adding another person to the pot—the protective service worker—is likely to change things by providing someone who will raise the other side of the issue rather than endorsing and legitimizing the process of sterilization. It is difficult to believe that the protective service worker will protect rights better than all of those other people serving as protectors. Perhaps it is enough to say that we cannot expect a total solution from protective service and should continue looking for solutions.

Another example is drawn from the recent furor over institutional conditions. Some courts are now saying that it is unconstitutional, and in many cases a violation of state statutes, to put people in warehouses where they have inadequate

health care, no rehabilitation programming, no prospect of re-entry into the community, and jobs which benefit the institution but not themselves. The situations in some institutions call for someone to stand up and speak on behalf of the rights of the retarded. Who might do it? The parents? Parents are often the prime mover in institutionalizing children. The courts also initiate institutionalization. The institution itself, appointed guardian, is clearly in a conflict of interest position. Many institutions now have protective service workers assigned to them, and it remains to be seen if the workers will become involved in protecting rights to care and treatment.

And finally, it remains to be seen *which* rights will be protected. The same evening I visited Cleveland General Hospital, I walked into a room where there were two parents, part of a committee suing the institution for a denial of the constitutional right to humane care and treatment. I told them what I had just learned about sterilization, and one of these advocates replied , "You'd better not do anything about that. I've referred four or five families over there, and if you try to do something, I want to make sure I get the next four over in the next week." In other words, someone who was operating as an effective advocate with respect to some rights was in a very different position with respect to another issue. This suggests the need for a multi-polar system of protection, but a multi-polar system is what we already have. Perhaps what is needed is civil liability for people who are supposed to act as advocates and do not do so. We do make lawyers pay money if they do not adequately protect rights, although we define failure to protect in a very narrow fashion. I am not really suggesting that we make protective service workers subject to heavy civil liability, but I am left with the question of how *all* rights can be protected and the nagging doubt that protective services is not the final answer.

THE OHIO PROTECTIVE SERVICE SYSTEM

How should the Ohio Protective Services System be evaluated within the context of control and individual rights? To begin with, the intentions of the sponsors of the bill and the motivations of protective service workers now in the field are no doubt high and beyond reproach. These motivations, however, are also irrelevant. We need another perspective. Let us assume that all the noble people are kicked out, and we are left with an administration which would like to get rid of the mentally retarded or control them and keep them out of circulation. Then we must look at the statute itself and ask this question: Does it provide an effective mechanism for *denying* the rights of the mentally retarded? I will offer the following loosely-organized list of matters which strike me as problematic in the Ohio system.

A. We should evaluate the costs of protection. Not only will the program cost a great deal of money, but it will have some payoffs in good service and some costs in bad service. It would be to our advantage to do a hard-headed evaluation in a couple of years to determine what the cost in dollars is and whether the program is worth the cost. We should determine the cost in terms of overcontrol of people's lives, as well as counting the number of people who have been pulled out of desparate situations.

B. We must also question the underlying rationale for protective services legislation. In a very important way, I see the bill as a response to fears—fear of death and fear of being penniless and dependent on welfare—fears which we have for ourselves and also have for retarded children. In establishing protective services, are we overreacting to normal fears by trying to create a security blanket? Weren't institutions built and maintained in part because they provided security to parents worried about the futures of their retarded children? We are no longer allowing people to be institutionalized as easily as they used to be, and suddenly we find ourselves wanting an alternative security system. Parents are saying, "Deinstitutionalization is fine, but then what?" I doubt that we can overcome our insecurities through protective services, and I know we cannot rationally expect it to solve the basic issues of income and death.

C. It seems clear to me that the Protective Services System has the potential for being used as a control system and used very indiscriminately with respect to people being moved from institutions to the community. Once a person is reached through protective services, the next logical step is to maintain contact and control. Phrases like "aggressive case-finding," "lifetime follow-along services," and "computer bank monitoring" suggest intensive supervision and control.

D. The control orientation of protective services is a contradiction of the principle of normalization. Normalization cannot be restricted to having "normal" baths, meals, and living rooms. It implies the right to make decisions and make mistakes. Normalization in materialistic terms is not enough. What is normal is freedom and the right to decide, and thus there is a contradiction between the normalization principle and the provisions for substitute decision-makers in the protective services system.

E. The legislation as written has a strong voluntary element in it which I believe is deceptive. It is a coercive system couched in the language of a voluntary system. In the first place, all kinds of people in authority can initiate protective services. Then, suppose the person protected says, "I want out." At this point, the protective service worker has the right to take all of the information gathered within the framework of a "voluntary" relationship into court, and argue that the person does not know what is best for him and actually needs a protector or guardian involuntarily appointed. If the goal is a voluntary helping relationship which allows the retarded to choose, the compulsory back-up club must be removed. And while I am on the matter of terminating protective services relationships, it is shocking that the statute requires that a request for termination be submitted in writing. Not only does it smack of discrimination against the retarded, but it hints at the broader difficulties in insuring voluntary initiation and termination of the service.

F. The statute has a clear potential for conflict of interest. The conclusions of the San Sebastian Conference, as well as the United Nations Declaration of Rights, indicate which persons are not suitable as guardians for the mentally retarded because of the possibility of conflict of interest. The list includes those who are performing a service for the ward—a physician, teacher, landlady, superintendent, attorney, or anyone employed in one of the service systems in which the ward is enrolled. Perhaps Ohio would have us believe that departments within the Division of Mental Retardation are distinct service systems, but it seems obvious that protective service workers and other employees answer to the same administrators.

Surely the government cannot serve as a protector or guardian without conflicts of interest arising. The clearest illustration of this is to ask how long we must wait for the "protectors" to sue the institutions for deplorable and unconstitutional levels of "service" to residents.

G. Another conflict of interest issue is perhaps more subtle. What does a protective service worker do when two of the people he protects have different interests? For a person with an I.Q. of 30, the worker may advocate the development of a segregated special school, while for a person with an I.Q. of 49 he may argue for integration within the school system. If a worker has fifty clients, how is he to represent them all adequately and equally? Conflict of interest is handled by various mechanisms in the legal profession, but I do not see that appropriate mechanisms have been developed with respect to protective services.

H. The Ohio statute has a pervasive vagueness that creates grave dangers of abuse. One area of vagueness in the act is its definition of the powers of guardians and protectors. Does a guardian have the right to decide where a person should live or whether he or she should be institutionalized, whether he or she should marry or marry a specific individual, whether he or she should be sterilized or submit to contraception? It seems clear that the protector does not have all of these powers, but the powers of protectors and guardians are unclear.

I. A second area of vagueness, and final criticism, is in terms of who is to receive protective services and by what process. According to the statute, the probate court will make decisions affecting a "person in need of protective services." There are no further standards, except a brief list of types of incompetence. There is a definition of "mentally retarded or other developmentally disabled person," but as we have noted before, protective services are not for all of the mentally retarded. No standards or procedures are laid out which would help the probate court make its decision. In fact, the statute does not even clearly give the probate court the power to do what the Division of Mental Retardation has the power to ask the court to do. Does the person who is about to be assigned to a protector have the right to an attorney, a jury trial, or proof beyond a reasonable doubt?

Many of these issues are the kinds of technical matters which occur to a lawyer, but they also suggest to me the need for more thorough planning in establishing protective service models. Again, I would emphasize the need for reading any proposed statute as though the program were going to be staffed with tyrants and applied to all citizens, so that proper safeguards are built in from the beginning. We must ask if we are endorsing a system for the retarded which we would not want applied to us. I am strongly in favor of providing good social services, but a law such as the Ohio statute may represent a dangerous kind of overkill. Perhaps I have not offered any solutions, but I hope that I have raised the right kinds of questions.

Appendix A Ohio's Protective Service Law

(Amended House Bill No. 290)

AN ACT

To amend sections 2109.01, 2109.04, 2111.01, and 2111.05 and to enact sections 5119.85 to 5119.89, inclusive, of the Revised Code to establish a protective service and public guardianship program in the division of mental retardation.

Be it enacted by the General Assembly of the State of Ohio:

SECTION 1. That sections 2109.01, 2109.04, 2111.01, and 2111.05 be amended and sections 5119.85, 5119.86, 5119.87, 5119.88 and 5119.89 of the Revised Code be enacted to read as follows:

Sec. 2109.01. "Fiduciary" as used in Chapters 2101. to 2131., inclusive, of the Revised Code, means any person, association, or corporation, other than an assignee or trustee for an insolvent debtor or a guardian under sections 5905.01 to 5905.19, inclusive, of the Revised Code, appointed by and accountable to the probate court and acting in a fiduciary capacity for any person, association, or corporation, or charged with duties in relation to any property, interest, trust, or estate for the benefit of another; AND INCLUDES THE DIVISION OF MENTAL RETARDATION OR AN AGENCY UNDER CONTRACT WITH THE DIVISION FOR THE PROVISION OF PROTECTIVE SERVICE UNDER SECTIONS 5119.85 TO 5119.89, INCLUSIVE, OF THE REVISED CODE, APPOINTED BY AND ACCOUNTABLE TO THE PROBATE COURT AS GUARDIAN OR TRUSTEE WITH RESPECT TO MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED PERSONS.

Sec. 2109.04. Unless otherwise provided by law, every fiduciary shall, prior to the issuance of his letters as provided by section 2109.02 of the Revised Code, file in the probate court in which the letters are to be issued a bond with a penal sum in such amount as may be fixed by the court, but in no event less than double the probable value of the personal estate and of the annual real estate rentals which will come into such person's hands as a fiduciary. The penal sum of the bond of a guardian of the person only shall be double the probable expenditures to be made by such guardian for the ward during one year. Such bond shall be in a form approved by the court and signed by two or more personal sureties or by one or more corporate sureties approved by the court and shall be conditioned that the fiduciary will faithfully and honestly discharge the duties devolving upon him as such fiduciary, and shall be conditioned further as may be provided by law; provided that if the instrument creating the trust dispenses with the giving of a bond the court shall appoint a fiduciary without bond, unless the court is of the opinion that the interest of the trust demands it, in which event the court may require bond to be given in such amount as may be fixed by the court.

When an executive secretary who is responsible for the administration of CHILDREN services in the county is appointed as trustee of the estate of a ward pursuant to section 5153.18 of the Revised Code, and has furnished bond under section 5153.13 of the Revised Code, OR WHEN THE DIVISION OF MENTAL RETARDATION OR AN AGENCY UNDER CONTRACT WITH THE DIVISION FOR THE PROVISION OF PROTECTIVE SERVICE UNDER SECTIONS 5119.85 TO 5119.89, INCLUSIVE, OF THE REVISED CODE IS APPOINTED AS TRUSTEE OF THE ESTATE OF A WARD UNDER SUCH SECTIONS AND ANY EMPLOYEES OF THE DIVISION OR AGENCY HAVING CUSTODY OR CONTROL OF FUNDS OR PROPERTY OF SUCH A WARD HAVE FURNISHED BOND UNDER SECTION 5119.89 OF THE REVISED CODE, the court may dispense with the giving of a bond.

When letters are granted without bond, at any later period on its own motion or upon the application of any party interested, the court may require bond to be given in such amount as may be fixed by the court. On failure to give such bond the defaulting fiduciary shall be removed.

No instrument authorizing a fiduciary therein named to serve without bond shall relieve a successor fiduciary from the neccessity of giving bond, unless the instrument clearly evidences such intention.

The court by which a fiduciary is appointed may reduce the amount of the bond of such fiduciary at any time for good cause shown.

When two or more persons are appointed as joint fiduciaries, the court may take a separate bond from each or a joint bond from all.

Sec. 2111.01. As used in Chapters 2101. to 2131., inclusive, of the Revised Code:

(A) "Guardian," other than a guardian under sections 5905.01 to 5905.19, inclusive, of the Revised Code, means any persons, association, or corporation appointed by the probate court to have the care and management of the person, the estate, or both of an incompetent or minor, OR THE DIVISION OF MENTAL RETARDATION OR AN AGENCY UNDER CONTRACT WITH THE DIVISION FOR THE PROVISION OF PROTECTIVE SERVICE UNDER SECTIONS 5119.85 TO 5119.89, INCLUSIVE, OF THE REVISED CODE APPOINTED BY THE PROBATE COURT TO HAVE THE CARE AND MANAGEMENT OF THE PERSON OF AN INCOMPETENT.

(B) "Ward" means any person for whom a guardian as defined in this section is acting.

(C) "Resident guardian" means a guardian appointed by a probate court to have the care and management of property in Ohio belonging to a nonresident ward.

(D) "Incompetent" means any person who by reason of advanced age, improvidence, or mental or physical disability or infirmity, chronic alcoholism, mental retardation, lunacy, or mental illness, is incapable of taking proper care of himself or his property or fails to provide for his family or for other persons for whom he is charged by law to provide, or any person confined to a penal institution within this state, or any person indeterminately hospitalized pursuant to section 5122.15 of the Revised Code and not subsequently found competent, pursuant to section 5122.36 of the Revised Code.

Sec. 2111.05. When the whole estate of a ward or of several wards jointly, under the same guardianship, does not exceed one thousand dollars in value, the guardian may apply to the probate court for an order to terminate said guardianship. Upon proof that it would be for the best interest of the ward to terminate the guardianship, the court may order the guardianship terminated and direct the guardian, if such ward is a minor, to deposit the assets of such guardianship in a depository authorized to receive fiduciary funds payable to the ward when he attains majority, or the court may authorize the delivery thereof to the natural guardian of the minor, to the person by whom the minor is maintained, to the executive secretary of CHILDREN services in the county, or to the minor himself.

If the ward is an incompetent, and the court orders said guardianship terminated, the court may authorize the deposit thereof in a depository authorized to receive fiduciary funds in the name of a suitable person to be designated by the court, or if the assets do not consist of money, the court may authorize the delivery thereof to a suitable person to be designated by the court. The person receiving such money or other assets shall hold and dispose of the same in such manner as the court directs.

If the court refuses to grant such application to terminate the guardianship, or if no such application is presented to the court, the guardian shall only be required to render account upon the termination of his guardianship, upon order of the probate court made upon its own motion, or upon the order of the court made on the motion of a person interested in the wards or their property, for good cause shown, and set forth upon the journal of the court.

If the estate is one of one thousand dollars or less and the ward is a minor, the court may, without the appointment of a guardian by the court or the giving of bond, authorize the deposit thereof in a depository authorized to receive fiduciary funds payable to the guardian when appointed or to the ward when he attains majority, or the court may authorize the delivery thereof to the natural guardian of the minor, to the person by whom the minor is maintained, to the executive secretary who is responsible for the administration of CHILDREN services in the county, TO THE DIVISION OF MENTAL RETARDATION OR THE ADMINISTRATOR OF AN AGENCY UNDER CONTRACT WITH THE DIVISION FOR THE PROVISION OF PROTECTIVE SERVICE UNDER SECTIONS 5119.85 TO 5119.89, INCLUSIVE, OF THE REVISED CODE, or to the minor himself.

If the whole estate of a person over twenty-one years of age, who has been adjudged mentally ill or MENTALLY RETARDED, does not exceed one thousand dollars in value, the court may, without the appointment of a guardian by the court or the giving of bond, authorize the deposit thereof in a depository authorized to receive fiduciary funds in the name of a suitable person to be designated by the court, or if the assets do not consist of money, the court may authorize the delivery thereof to a suitable person to be designated by the court. The person receiving such money or other assets shall hold and dispose of the same in such manner as the court directs.

Sec. 5119.85. AS USED IN SECTIONS 5119.85 TO 5119.89, INCLUSIVE, OF THE REVISED CODE:

(A) "MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON" MEANS ANY INDIVIDUAL HAVING A DISABILITY ATTRIBUTABLE TO MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY, OR ANOTHER NEUROLOGICAL CONDITION CLOSELY RELATED TO MENTAL RETARDATION OR REQUIRING TREATMENT SIMILAR TO THAT REQUIRED FOR MENTALLY RETARDED INDIVIDUALS, WHICH HAS CONTINUED OR CAN BE EXPECTED TO CONTINUE INDEFINITELY AND CONSTITUTES A SUBSTANTIAL HANDICAP.

(B) "GUARDIAN" MEANS GUARDIAN OF THE PERSON PURSUANT TO APPOINTMENT BY THE PROBATE COURT UNDER CHAPTER 2111. OF THE REVISED CODE.

(C) "TRUSTEE" MEANS A TRUSTEE APPOINTED BY AND ACCOUNTABLE TO THE PROBATE COURT, IN LIEU OF A GUARDIAN AND WITHOUT A JUDICIAL DETERMINATION OF INCOMPETENCY, WITH RESPECT EITHER TO AN ESTATE OF THREE THOUSAND DOLLARS OR LESS OR TO PERIODIC PAYMENTS OF NOT MORE THAN FORTY DOLLARS PER WEEK, OR BOTH.

(D) "PROTECTOR" MEANS THE DIVISION OF MENTAL RETARDATION OR AN AGENCY UNDER CONTRACT WITH THE DIVISION ACTING WITH OR WITHOUT COURT APPOINTMENT TO PROVIDE GUIDANCE, SERVICE, AND ENCOURAGEMENT IN THE DEVELOPMENT OF MAXIMUM SELF-RELIANCE TO A MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON, INDEPENDENT OF ANY DETERMINATION OF INCOMPETENCY.

(E) "PROTECTIVE SERVICE" MEANS PERFORMANCE OF THE DUTIES OF A GUARDIAN OR TRUSTEE, OR ACTING AS A PROTECTOR, WITH RESPECT TO A MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON.

Sec. 5119.86. THE DIVISION OF MENTAL RETARDATION SHALL DEVELOP A STATE-WIDE SYSTEM OF PROTECTIVE SERVICE IN ACCORDANCE WITH REGULATIONS AND STANDARDS ESTABLISHED BY THE DIVISION. WITH RESPECT TO THIS PROGRAM, THE DIVISION MAY:

(A) PROVIDE DIRECT SERVICES;

(B) ENTER INTO A CONTRACT WITH ANY RESPONSIBLE AGENCY, PUBLIC OR PRIVATE, FOR PROVISION OF PROTECTIVE SERVICE BY THE AGENCY;

(C) ACCEPT APPOINTMENT BY ANY PROBATE COURT AS GUARDIAN, TRUSTEE, PROTECTOR, OR TRUSTEE AND PROTECTOR OF A MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON.

Sec. 5119.87. NO GUARDIANSHIP OR TRUSTEESHIP APPOINTMENT SHALL BE MADE UNDER SECTIONS 5119.85 TO 5119.89, INCLUSIVE, OF THE REVISED CODE AND NO PERSON SHALL BE ACCEPTED FOR SERVICE BY A PROTECTOR UNDER SUCH SECTIONS UNLESS A COMPREHENSIVE EVALUATION HAS BEEN MADE IN A CLINIC OR OTHER FACILITY APPROVED BY THE DIVISION OF MENTAL RETARDATION. THE

EVALUATION SHALL INCLUDE A MEDICAL, PSYCHOLOGICAL, SOCIAL, AND EDUCATIONAL EVALUATION, AND A COPY OF SUCH EVALUATION SHALL BE FILED WITH THE DIVISION OF MENTAL RETARDATION.

THE DIVISION OR AGENCY SHALL PROVIDE FOR A REVIEW AT LEAST ONCE EACH YEAR IN WRITING OF THE PHYSICAL, MENTAL, AND SOCIAL CONDITION OF EACH MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON FOR WHOM IT IS ACTING AS GUARDIAN, TRUSTEE, OR PROTECTOR. CONTRACTING AGENCIES SHALL FILE THESE REPORTS WITH THE DIVISION OF MENTAL RETARDATION. ANY RECORD OF THE DIVISION OR AGENCY PERTAINING TO SUCH A PERSON SHALL NOT BE A "PUBLIC RECORD" UNDER SECTION 149.43 OF THE REVISED CODE. INFORMATION CONTAINED THEREIN SHALL NOT BE DISCLOSED PUBLICLY IN SUCH A MANNER AS TO IDENTIFY INDIVIDUALS, BUT MAY BE MADE AVAILABLE TO PERSONS APPROVED BY THE COMMISSIONER OF MENTAL RETARDATION OR THE COURT.

Sec. 5119.88. THE DIVISION OF MENTAL RETARDATION OR AN AGENCY PROVIDING PROTECTIVE SERVICES UNDER CONTRACT WITH THE DIVISION MAY BE NOMINATED UNDER ANY OF THE FOLLOWING CONDITIONS AS GUARDIAN, TRUSTEE, OR PROTECTOR, OR AS TRUSTEE AND PROTECTOR OF A MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON:

(A) THE PERSON WHO NEEDS OR BELIEVES HE NEEDS PROTECTIVE SERVICE MAY MAKE APPLICATION IN WRITING.

(B) ANY INTERESTED PERSON MAY MAKE APPLICATION IN WRITING ON BEHALF OF A MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON.

(C) A PARENT MAY NAME THE DIVISION OR AGENCY AS GUARDIAN, OR SUCCESSOR GUARDIAN IN A WILL.

(D) A PARENT MAY NAME THE DIVISION OR AGENCY AS GUARDIAN, TRUSTEE, OR PROTECTOR, TO ASSUME SUCH DUTIES DURING THE PARENT'S LIFETIME.

IF THE RESULTS OF THE COMPREHENSIVE EVALUATION REQUIRED UNDER SECTION 5119.87 OF THE REVISED CODE INDICATE THAT THE PERSON NAMED IN THE NOMINATION IS IN NEED OF PROTECTIVE SERVICES, THE DIVISION OR AGENCY SHALL EITHER REJECT OR ACCEPT THE NOMINATION AS GUARDIAN OR TRUSTEE, SUBJECT TO APPOINTMENT BY THE PROBATE COURT, OR REJECT OR ACCEPT THE NOMINATION AS PROTECTOR, OR TRUSTEE AND PROTECTOR.

AT THE TIME THE NOMINATION IS ACCEPTED OR WHEN AN APPOINTMENT IS MADE BY THE COURT, THE MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON AND ANY PERSON WHO MADE APPLICATION FOR SERVICE ON HIS BEHALF UNDER THIS SECTION SHALL BE INFORMED BY THE DIVISION, AGENCY, OR COURT OF THE PROCEDURE FOR TERMINATING THE APPOINTMENT OR SERVICE. THE DIVISION OR AGENCY SHALL CEASE TO PROVIDE PROTECTIVE SERVICE AS A PROTECTOR PURSUANT TO NOMINATION UNDER DIVISION (A), (B),

OR (D) OF THIS SECTION WHEN A WRITTEN REQUEST FOR TERMINATION IS RECEIVED BY THE DIVISION OR AGENCY FROM OR ON BEHALF OF THE MENTALLY RETARDED OR OTHER DEVELOPMENTALLY DISABLED PERSON. IF THE DIVISION OR AGENCY BELIEVES THE PERSON TO BE IN NEED OF PROTECTIVE SERVICE, THE DIVISION OR AGENCY MAY FILE AN APPLICATION FOR GUARDIANSHIP, TRUSTEESHIP, OR PROTECTORSHIP WITH THE PROBATE COURT. TERMINATION OF ANY COURT APPOINTMENT AS GUARDIAN, TRUSTEE, OR PROTECTOR MUST BE BY ORDER OF THE PROBATE COURT.

Sec. 5119.89. BEFORE ENTERING UPON THE DUTIES OF TRUSTEE, THE DIVISION OF MENTAL RETARDATION OR AN AGENCY UNDER CONTRACT WITH THE DIVISION MAY REQUIRE ANY OF ITS EMPLOYEES HAVING CUSTODY OR CONTROL OF FUNDS OR PROPERTY TO GIVE BOND TO THE PROBATE COURT WITH SUFFICIENT SURETY, CONDITIONED UPON THE FULL AND FAITHFUL ACCOUNTING OF ALL TRUST FUNDS WHICH HE HOLDS. THE AMOUNT OF SUCH BOND SHALL BE DETERMINED BY THE COURT AND MAY BE MODIFIED BY THE COURT.

SECTION 2. That existing sections 2109.01, 2109.04, 2111.01, and 2111.05 of the Revised Code are hereby repealed.

CHARLES F. KURFESS,
Speaker of the House of Representatives.

JOHN W. BROWN,
President of the Senate.

Passed December 8, 1971.

Approved December 23, 1971.

JOHN J. GILLIGAN,
Governor.

The sectional numbers herein are in conformity with the Revised Code.

OHIO LEGISLATIVE SERVICE COMMISSION
DAVID A. JOHNSTON, *Director*

Filed in the office of the Secretary of State at Columbus, Ohio, on the 23rd day of December, A. D. 1971.

I hereby certify that the foregoing is a true copy of the enrolled bill.

TED W. BROWN,
Secretary of State.

File No. 198. Effective March 23, 1972.